

A Pilot Study of MY VOICE:  
Strengths-Based and Self-Directed Recovery Planning

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Dissertation

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Strengths-Based and Self-Directed Recovery Planning

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### **Abstract**

An imbalance of power and autonomy exists between individuals with psychiatric disabilities and their treatment providers. Electronic decision support interventions (EDSI's) help individuals with psychiatric disabilities increase consumer self-determination and decision-making in care. The MY VOICE: Strengths-based and Self-Directed Recovery Planning is an EDSI designed to assist consumers in writing their own recovery plans. The purpose of this randomized waitlist controlled pilot study of the MY VOICE program was to test the hypothesis that participation in a self-directed EDSI program will lead to increases in consumer self-identified empowerment, self-determination and recovery. Findings indicate that participation in the MY VOICE program in comparison to the control group was a significant predictor of consumer self-identified recovery while participation in MY VOICE was not a significant predictor of self-identified empowerment or self-determination. The number of tasks a person completes and completion of the program itself were also not predictors of self-identified empowerment, self-determination, or recovery. Future research may need to control for the relationship with the peer-support worker facilitating the MY VOICE program, endeavor to determine elements within the MY VOICE program that facilitate increases in self-identified recovery, and conduct qualitative analysis to better understand how participants are using their self-directed recovery plans and how they view the MY VOICE program and the peer support facilitator influencing them.

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the school's rich history of researching self-determination, strengths-based practice, and interventions that assist individuals with psychiatric disabilities.

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## Table of Contents

Abstract.....	iii
Acknowledgments.....	iv
Table of Contents.....	vii
Chapter 1: Introduction and Overview.....	1
Chapter 2: Literature Review and Theoretical Framework .....	5
Empowerment.....	5
Self-Determination.....	8
Recovery.....	10
Strengths.....	12
Self-Directed Care and Shared-Decision Making.....	14
The Self-Directed Care Model.....	15
Elements of SDC in the MY VOICE Program.....	18
Empirical Support of Self-Directed Care.....	18
The Shared-Decision Making Model.....	24
Elements of SDM in the MY VOICE Program.....	26
Empirical Support of Shared-Decision Making.....	26
Research on Electronic Decision Support Centers.....	32
Critical Analysis.....	37
Description of The MY VOICE program.....	40
Research Questions.....	43
Chapter 3: Methodology .....	45
Participants.....	45

Design.....	49
Instrumentation.....	51
Procedures.....	54
Analysis.....	56
Chapter 4 Results .....	61
Demographic Results.....	61
Question 1: Demographic Predictors.....	64
Question 2: Differences Between Intervention and Control.....	65
Questions 3 and 4 Completion of Program and Completion of Tasks.....	68
Chapter 5: Discussion .....	77
Limitations and Strengths.....	77
Discussion of Salient Findings.....	79
Relevance to Social Work.....	87
Implications.....	89
Practice.....	89
Policy.....	91
Research.....	92
Conclusions.....	95
References.....	97
Appendices.....	115



## **Chapter 1: Introduction and Overview**

A lack of personal power, choice, control and autonomy has characterized the historic treatment of individuals with psychiatric disabilities and there continues to be an imbalance of power in mental health care between treatment providers and those receiving care (Strickler, 2009). While major strides to increase consumer empowerment and independence have occurred during the past century, there is much room for improvement. Individuals with psychiatric disabilities indicate that they want more say in their treatment (Klein, Rosenberg, & Rosenberg, 2007; Hamann, Cohen, Leucht, Busch, & Kissling, 2005, 2007; Adams, 2007; Noble, 2004; O'Neal, Adams, McHugo, Van Citters et al., 2008), including having information about providers and whether or not the providers are amenable to collaborative decision making (Stein, Kogan, Essock, & Fudurich, 2009). Approximately one-third of consumers disengage from care (Kreyenbuhl et al., 2009) which has been partially attributed to a lack of consumer self-determination, choice and power sharing (Roe et al., 2009).

Electronic decision support interventions (EDSI's) have been developed to help consumers increase consumer self-determination and decision-making in care (Drake, Deegan, & Rapp, 2010). While initial studies have shown that most consumers are capable of using EDSI's (Adams, 2006; Deegan, 2007, Woltman et al., 2010) no published studies have reported specific consumer characteristics which may predict EDSI completion. In addition, while empowerment, self-determination, and recovery are included in the rationale for consumer participation in EDSI's, no known studies have directly explored whether participation in an EDSI will actually lead to consumer identified increases in empowerment, self-determination, and recovery; nor do known EDSI's currently available to consumers explicitly include a focus on consumer strengths.

Empowerment can be defined as a client moving away from passive acceptance of oppressive circumstances and instead becoming engaged in obtaining power which can enable action towards change (Gutierrez, 1990). In the context of psychiatric disability this means helping individuals become emboldened to take the reins over their diagnoses and treatment. Self-determination has been defined in a variety of ways, such as an individual's right to make his/her own decisions, his/her right to actively participate in the helping process, and his/her right to lead a life of his/her own choosing (Weick & Pope, 1988). Recovery can be defined as being connected to the community in meaningful ways; having an identity separate from one's condition; and having a life that is satisfying, fulfilling, and contributing to others in spite of or within the limitations imposed by a psychiatric disability (Davidson, Tondora, & O'Connell, 2007). Strengths can be defined as any capacity, quality, resource, knowledge, or asset that can assist individuals in dealing with the challenges in life (Saleebey, 2001). This means that just about anything that individuals with a psychiatric disability find helpful in their progress towards recovery could be defined as a strength.

The MY VOICE: Strengths-based and Self-Directed Recovery project is an EDSI program developed in Kansas to help consumers write their own recovery plans. The MY VOICE EDSI was developed in order to address concerns that consumers 1) often are disempowered and lack opportunities for self-determination in treatment, 2) do not have an EDSI available which focuses on consumer strengths, and 3) do not have an EDSI available which helps facilitate self-determined recovery planning.

The MY VOICE program is an internet accessed software program which guides consumers through a self-directed recovery goal planning process. Consumer's strengths are assessed and linked to their recovery goals to help them develop an initial recovery plan. The

plan includes self-identified steps consumers can take to begin or continue their recovery journey. Consumers can then print out or email a list of their strengths and/or their initial recovery plan and share them with whomever they want. Consumers can go through the MY VOICE process as many times as they choose and can do so at will. Once consumers receive a login name and password and have gone through the program once, they are able to access it from almost any internet connection (for instance a home computer, the local library, or a coffee shop).

MY VOICE incorporates elements from two emerging trends in psychiatric rehabilitation which may help increase individuals' control over their treatment and recovery: (1) Self-Directed Care (SDC), and (2) Shared-Decision Making (SDM). Self-directed care is a method of delivery for community mental health services that emphasizes participants' ability to manage their own health care. Shared-decision making is a model of collaborative treatment which involves at least two people which includes information for making a decision (which can include electronic decision making interventions), an interactive process of discussing and generating a shared decision, and systematic opportunities to review and revise decisions after they are made (Curtis et al., 2010). From SDC, the MY VOICE program borrows the concepts of informed self-assessment and determining how and by whom consumer needs should be met. From SDM, MY VOICE borrows a focus on technological decision aids which help individuals increase their voice in treatment, make informed decisions, and facilitation of a decision making process.

The purpose of this randomized waitlist controlled design pilot study of the MY VOICE program is to test the hypothesis that participation in a self-directed EDSI program will lead to increases in consumer self-identified empowerment, self-determination and recovery. Specifically, this study is to test the relationship between participation in the MY VOICE:

Strengths-based and Self-Directed Recovery program with scores on the Empowerment Scale (Rogers, Ralph, & Salzer, 2010), the Self-Determination Scale (Sheldon, Ryan, & Reis, 1996) and the Self-Identified Stage of Recovery Scale (SIS-R) (Andresen, Caputi, & Oades, 2010) by adult consumers at an urban consumer run organization.

It is anticipated that the MY VOICE program will facilitate self-determination by providing a means for individuals to conduct a meaningful self-assessment of their strengths, identify their personal recovery goals, link their strengths to their goals and identify initial tasks toward goal completion. Because the MY VOICE EDSI is developed to focus on strengths and is self-directed, participation may lead to increases in client identified empowerment, self-determination, and recovery. In other words, individuals may feel emboldened to take control of their treatment, feel more in control of their lives, and feel their lives are more satisfying. In addition, after completing the MY VOICE program, consumers may then feel empowered to take their developed recovery plan and/or their list of strengths to any treatment interaction they choose and initiate a shared-decision making process.

The concepts introduced in this opening chapter will be discussed in more detail in Chapter 2, including empowerment, self-determination, strengths, recovery, self-directed care, shared-decision making, and electronic decision making interventions. It will be shown how each of these concepts are logically related to the MY VOICE program and are related to the conducted pilot study.

## **Chapter 2: Literature Review and Theoretical Framework**

The MY VOICE program was developed using concepts from Self-Directed Care and Shared-Decision Making, and merging them into an EDSI program which explicitly focuses on assessing and utilizing client strengths. It is anticipated that the utilization of the MY VOICE program may increase client identified empowerment, self-determination, and recovery. A review of the literature and examination of each of these underlying theoretical constructs is provided.

### **Empowerment**

Central to empowerment theory is the idea that interventions should focus on helping an individual move away from passive acceptance of oppressive circumstances and instead become engaged in obtaining sources of power which enable action towards change (Gutierrez, 1990). In the context of psychiatric disability this means helping consumers become emboldened to take the reins over their diagnoses and treatment.

Traditionally, empowerment theories have included a wide variety of ideas drawn from fields such as sociology, economics, political theory, liberation theology, and the social work tradition (Robbins, Chatterjee & Canda, 2012). All of these fields derived their conceptualizations of empowerment from early critical and Marxist thought, as well as from the concepts of consciousness raising and social action as developed by Paolo Friere (Friere, 1972). Empowerment is critical in its analysis of social institutions and power, and pragmatic in its focus on positive social outcomes and concern with praxis (Robbins, Chatterjee & Canda, 2012). Therefore, rather than focusing on prediction or description, empowerment theories are more concerned with application and action (Robbins, Chatterjee & Canda, 2012).

Producing change and building awareness of real-life circumstances are the primary goals of empowerment (Friere, 1972, 1973; Gutierrez & Ortega, 1991). Empowerment theories avoid blaming the victim (Solomon, 1976) and recognize that “the source of problems [are often] ...interactional with the structures and dynamics of society’s major social institutions, and that individuals have unequal power in relation to such institutions” (Parsons, 1991, p.9). If the difference in power between individuals and these social structures becomes too great, individuals may perceive themselves as being unable to act on their own behalves. The goal of empowerment then becomes the appropriation of ways in which individuals can act for themselves. Gutierrez (1990) defined empowerment as “the process of increasing personal, interpersonal, or political power so that individuals, families, and communities can take action to improve their situations (p. 202).” However, empowerment is not simply a process of appropriation; it is both a process and an outcome (Parsons, 1991).

In a review of the literature, Torre (1985) identified at least three themes of empowerment across a variety of fields: (1) a developmental process which begins with individual growth and possibly culminates in larger social change; (2) a psychological state marked by heightened feelings of self-esteem, efficacy, and control; and (3) liberation, resulting from a social movement which begins with education and politicization of powerless people, and later involves collective attempts on the part of the powerless to gain power, and to change those structures which remain oppressive. Torre defined empowerment as:

A process through which people become strong enough to participate within, share in control of, and influence, events and institutions affecting their lives, and that in part, empowerment necessitates that people gain particular skills, knowledge, and sufficient power to influence their lives and the lives they care about. (1985, p. 18)

Professor and social worker Lorraine Gutierrez identified a similar series of themes: (1) increasing self-efficacy (2) developing a critical consciousness (3) developing skills, and (4) involvement with similar others (Gutierrez, 1990).

Consumers report that they want more say in their mental health care decisions (Klien, Rosenberg, & Rosenberg, 2007) and often experience themselves as having no power and no real choices (Spaniol, 2008). “Loss of power is a loss of one’s ability to act in one’s own interest—this is a loss of belief in oneself. Loss of power is also the loss of one’s sense of agency and vitality—the inability to experience oneself as an active and vital agent” (Spaniol, 2008. p.59).

In general individuals with psychiatric disabilities are regarded as a disempowered, at risk, and marginalized population. Traditionally, mental health providers have been reluctant to allow individuals with psychiatric disabilities to make treatment decisions because of stereotypes about consumers’ ability to make rational choices, an unwillingness to give up the expert role, and the pejorative underpinning of working from a medical model. Long periods of institutionalization and exposure to paternalistic treatments have socialized some consumers to believe they are incapable of decision making or autonomy.

The MY VOICE program is designed to help empower individuals with psychiatric disabilities in several ways. First, the program is completely self-directed, meaning that consumers who participate are required to be the driver of their own recovery, no one else completes the program for them, with greater control being a primary component of empowerment (Torre, 1985). Second, the self-assessment of personal strengths makes explicit for participants what their strengths are and how they might be used toward goal attainment. Greater awareness of one's strengths and how to use them may lead to a changed psychological state such as increased self-efficacy and esteem; important beginning components of an

empowerment process (Gutierrez, 1990). This may lead to clients advocating for themselves in treatment interactions. While it is not tested in the current study, having a copy of one's self-directed recovery plan on hand prior to treatment planning, may provide a means for more collaborative decision making in mental health systems. This type of broad systems level change is the ultimate goal of later stages of an empowerment approach.

### **Self-Determination**

Another concept related to empowerment practice is self-determination (Robbins, Chatterjee, & Canda, 2012). Self-determination has been defined in a variety of ways, such as an individual's right to make his/her own decisions, his/her right to actively participate in the helping process, and his/her right to lead a life of his/her own choosing (Weick & Pope, 1988). These conceptions "contain a belief in the capacity and right of individuals to affect the course of their lives" (Weick & Pope, 1988. p. 10).

Early social workers such as Jane Addams and Bertha Capen Reynolds worked to eliminate oppression of minority groups. Part of their attempts included moving away from expert driven models of helping toward building a more equal and collaborative alliance in the helping relationship; meaning that the relationship included an emphasis on reciprocal learning and self-determination (Addams, 1893; Reynolds, 1951). Not only has self-determination been identified as a primary social work value (NASW, 2006); some have contended that one of social work's primary functions is to maximize opportunities for client self-determination (Freedberg, 1989). Self-determination is central to mental health and wellbeing (e.g. Swift, 2009) and is considered a basic human right (Adams, Grieder, Nerney, 2005). However, there are limitations placed on self-determination. For instance, Biestek (1957) makes several qualifying statements:



The client's right to self-determination, however, is limited by the client's capacity for positive and constructive decision making, by the framework of civil and moral law, and by the function of the agency. (p.103)

In other words, individuals can make their own choices as long as they conform to multiple layers of external mandates ranging from civil law, moral law, and agency policy. Central to these qualifiers is the assumption that the individual's capacity to make choices is suspect and that only others outside of the individual can objectively know what is best for the person receiving care. Individuals with psychiatric disabilities continue to struggle with stereotypes which depict them as being unable to make decisions and of course, there are limitations to self-determination when there is the potential for harm to self or others. However, nearly all individuals with a psychiatric disability, even the great majority of those with severe disorders such as schizophrenia, are capable of understanding treatment choices and making rational decisions (e.g. Carpenter, 2000; Grisso, 1995; Stroup, 2005). What is lacking is the willingness of agencies and providers to allow them to do so (Deegan, 2007) despite research indicating that with proper support the vast majority of individuals with psychiatric disabilities are capable of pro-social self-direction and decision making (Stefan, 2004). While there are some limitations placed on self-determination, there are very broad opportunities for self-determination within those limitations. The paradigm shift facilitated by SDM and SDC is to have the function of the agency to maximize self-determination whenever possible, rather than limit it. This is a major departure from historic agency functioning.

Individuals with psychiatric disabilities have the right to be at the center of the decisions that will affect their lives. The MY VOICE EDSI is designed to facilitate self-direction by placing the individual at the center of their own recovery. While a peer support worker is present to help the participant navigate the MY VOICE program, the participant does not have to gain

approval from the peer support provider, case managers, prescribers, or anyone else in the development of their recovery plan. MY VOICE is completely developed and driven by the participants' personal goals and values. Having complete choice, power, and control in the development of their recovery plan enables individuals to self-determine the course of their lives.

## **Recovery**

Within mental health and closely aligned with SDC and SDM is the idea of recovery. A program that facilitates recovery affords knowledge, skills, support, and resources to support the achievement of individuals' recovery goals (Spaniol, 2008). Davidson, Tondora, and O'Connell, (2007) describe recovery as being connected to the community in meaningful ways; having an identity separate from one's condition; and having a life that is satisfying, fulfilling, and contributing to others in spite of or within the limitations imposed by a mental illness. Recent consumer conceptualizations of recovery have moved away from medical model indicators such as symptoms, functioning, or hospitalizations. Instead, consumer-focused conceptualizations of recovery focus on the psychological aspects of recovery (Andresen, Caputi, & Oades, 2006) and tend to be more holistic in approach (e.g. Starnino, 2009).

There are a variety of tools used to measure these psychological aspects of recovery. For instance, The Recovery Assessment Scale (RAS) developed by Corrigan et al. (2004) yields a single continuous recovery score for individual consumers. Others measures assess programs (as opposed to consumers) on their ability to facilitate recovery. However, the majority of the recently developed measures conceptualize recovery as a series of non-linear stages which consumers pass through on their journey toward recovery (e.g. Andresen, Oades, & Caputi, 2003; Powell, 2009; Song & Hsu, 2011; Young & Ensing, 1999). When viewed as a series of stages, recovery is similar to empowerment: Individuals who are further along in the stages of

recovery have re-evaluated their self-image and moved away from viewing themselves as helpless in relation to their mental illness toward being influential. However, these stages are not necessarily linear; the recovery process is complex and often leads to individuals moving back and forth among the stages (Song & Hsu, 2011).

The Andresen, Oades, & Caputi (2003) scale provides a good example of a stages-of-recovery measure. They developed a recovery model based on consumer experiences by analyzing a large number of personal recovery stories as well as analyzing five qualitative studies which developed consumer-focused stages of recovery (studies analyzed included: Baxter & Diehl, 1998; Davidson & Strauss, 1992; Pettie & Triolo, 1999; Spaniol, Wewiorski, Gagne & Anthony, 2002; Young & Ensing, 1999). Once combined these studies were merged into a framework that included the following stages: (1) *Moratorium*: A time of withdrawal characterized by a profound sense of loss and hopelessness, (2) *Awareness*: Realization that all is not lost, and that a fulfilling life is possible, (3) *Preparation*: Taking stock of strengths and weaknesses regarding recovery, and starting to work on developing recovery skills, (4) *Rebuilding*: Actively working towards a positive identity, setting meaningful goals and taking control of one's life, and (5) *Growth*: Living a full and meaningful life, characterized by self-management of the illness, resilience and a positive sense of self (Andresen, Caputi, & Oades, 2006, p. 973). These five stages have since been validated through three separate measures: The Stages of Psychological Recovery Instrument (STORI) (Andresen, Caputi, & Oades, 2006), the Short Interview to assess Stage of Recovery (SIST-R), (Wolstencroft, Oades, Caputi, & Andresen, 2010) and the Self-Identified Stage of Recovery measure (SIS-R) (Andresen, Caputi & Oades, 2010).

The MY VOICE program may facilitate increases in self-identified recovery because individuals are literally developing recovery goals. As the tasks developed in MY VOICE are completed consumers move closer to completing recovery goals and it is logical to think that participants will feel like their recovery is progressing. While these stages of recovery are not necessarily linear it may be that the more goals and tasks that are completed through the MY VOICE program the more time individuals will spend in later recovery stages. Many of the recovery goals that individuals develop may involve being connected to the community in meaningful ways, help develop an identity separate from their disability, and may lead to a more fulfilling life in spite of or within the limitations of their disability all of which are important aspects of recovery (Davidson, Tondora, & O'Connell, 2007).

### **Strengths Perspective**

An important component of an empowerment-based approach is to rely on the consumer's existing strengths toward achieving the envisioned empowerment goals (Robbins, Chatterjee, & Canda, 2012). An exploration of strengths helps consumers recognize past successes, current environmental assets, and current skills (Rapp & Goscha, 2006). The recognition of one's strengths is hope inducing (Saleebey, 2006) and an individual who has hope for the future is less likely to be complacent or be a passive recipient of care (Rapp & Goscha, 2006). Therefore, focusing on strengths is an important factor to consider when helping individuals become empowered (Greene, Lee, & Hoffpauir, 2005). Assessing for and using strengths is the central tenet of the strengths perspective. Saleebey (2010) posits that operating from the strengths perspective means that "everything you do as a helper will be based on facilitating the discovery and embellishment, exploration, and use of clients' strengths and resources in the service of helping them achieve their goals and realize their dreams" (p.1). In

addition, central to the strengths perspective is the belief that clients are most successful at achieving their goals when they identify and utilize their strengths, abilities, and assets (Rapp, 2006).

Although components of the strengths perspective have been discussed in the social work literature periodically through much of its history, strengths-based work was not formalized into a set of practice principles until the 1980s (Rapp et al., 2005). The formalization of strengths perspective principles came in response to the pathology laden treatments available for individuals with psychiatric disorders prevalent at that time (Weick, Rapp, Sullivan, & Kisthardt, 1989). The strengths perspective was a position taken to challenge a mental health system that overly focused on diagnosis, deficits, labeling and problems (Saleebey, 2000; 2001). Initially implemented in case-management, the strengths perspective was integrated into other areas of social work and the helping professions (Saleebey, 1996).

The strengths perspective is predicated on a set of values and principles that have been operationalized in interventions such as strengths-model case management (SMCM) (Rapp & Goscha, 2006). The conceptualization of strengths as an overarching perspective has garnered critique from researchers (see Staudt et al., 2001) who contend that it is difficult to assess a direct relationship between the strengths perspective and outcomes (Probst, 2009). Despite this critique, there are studies which have shown positive results. Four experimental, four quasi-experimental, and three non-experimental design studies have been conducted on SMCM which show positive outcomes (Barry, Zeber, Blow, & Valenstein, 2003; Bjorkman, Hansson, & Sandlund, 2002; Kisthardt, 1994; Fukui, Goscha, Rapp, Mabry, Liddy, & Marty, 2012; Macias et al, 1994; Macias, Farley, Jackson, & Kinney, 1997; Modrcin, Rapp, & Poertner, 1988; Rapp & Chamberlain, 1985; Rapp & Wintersteen, 1989; Ryan, Sherman, & Judd, 1994; Stanard, 1999).

The MY VOICE program is explicitly strengths-based. Participants have the option of entering in a strengths assessment into the program if they have already filled out a strengths assessment with a case-manager prior to enrolling in the MY VOICE program. Participants are then asked to identify additional strengths. Consistent with the strengths perspective, the program helps participants set goals and link their identified strengths to the achievement of these goals. The program asks participants to identify goals within the same seven domains identified in SMCM, domains are labeled: Home/Daily Living, Assets/Finances/Insurance, Employment/Education, Supportive Relationship, Wellness/Health, Leisure/Recreation, and Spirituality/Culture (Rapp & Goscha, 2006). Participants then narrow their goals by prioritizing their top three goals. Once their top three goals are prioritized their identified strengths are linked to their goals and initial tasks are developed toward goal completion. After initial enrollment participants enter the program at any time and update their goals, strengths, and tasks.

### **Self-Directed Care and Shared-Decision Making**

In addition to an explicit focus on strengths, components of both Self-Directed Care (SDC) and Shared-Decision Making (SDM) were utilized in the development of the MY VOICE EDSI program. Self-Directed Care and SDM are two options that encourage person-centered mental health services. Person-centeredness is an umbrella term that includes interventions that place the person receiving services at the center of their treatment. Self-directed care and SDM are examples of person-centered care in that they ensure that individuals have genuine choices and thereby increase individuals' power and control over their lives. Given the emphasis in SDC and SDM on increasing personal power and control it is not surprising that, in addition to being person-centered, SDC and SDM make claim to being grounded in empowerment, self-direction and recovery (SAMHSA, 2004, 2010).

While SDC and SDM are related both of these models need to be discussed separately. There are very few published studies of SDC specific to mental health while in the case of SDM, many published studies are available for review. The examination of the SDC and SDM literature is organized by 1) describing the model, 2) describing which components of the model the MY VOICE program borrows and then 3) reviewing the overarching empirical support for the model. Self-Directed Care is reviewed first and is followed by a review Shared-Decision Making.

### **The Self-Directed Care Model.**

Self-directed care (SDC) is a method of delivery for community mental health services that emphasizes participants' ability to manage their own health care. The 2004 Consumer Direction Initiative Summit, Transforming Behavioral Health Care to Self-Direction (SAMHSA, 2004) defined the term SDC as a system that is intended to "allow informed consumers to assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services they receive" (Dougherty, 2003, p. 3). Participants use funds which are annually deposited into accounts allocated specifically for their use to purchase individualized healthcare packages. This model is consistent with current trends in health and behavioral health financing where the money follows the person (Cook & Jonikas, 2002).

Self-directed care in mental health has been implemented to serve uninsured low-income adults with psychiatric disabilities (Coakley, 2009). Participants in SDC program continue to have their clinical mental health care covered by Medicaid; and participants also have a set spending account from which to pay for any additional services. Ideally, participants choose from a variety of service options, such as supports for independent living, other therapies not covered by Medicaid, other healthcare not covered by Medicaid, job or computer training, and

wellness services. More detailed examples of these types of services might include housework assistance, cooking assistance, transportation, assistive technologies, speech therapy, physical therapy, occupational therapy, dental care, vision care, gym memberships, and smoking cessation (Cook et al. 2010).

Annual amounts paid to participants vary depending on existing funding schemes in the states where SDC has been implemented. The funded participant works with a coach or broker trained in the SDC program to purchase services related to disability related needs (Barczyk & Lincove, 2010). Together the coach and participant create a spending plan for the total amount deposited into the participant's account. As consumers access services, coaches offer advice on recruiting, hiring, training, supervising, and firing service providers (Phillips et al., 2003). It is important that the coach ensure that the services chosen are consistent with the recovery and life goals of the participant (Cook et al., 2008). The service plan should not be pre-selected. Some SDC service delivery plans use a peer-support worker as the coach in charge of assisting the development of the personalized service plans (Coakley, 2009). Person centered recovery planning is the essential first step in a self-directed care program. If adequate person centered planning does not occur, or the spending plans are chosen for the participant by the coach, self-directed care is no longer occurring. The consumer can also maintain a benefit account and in some instances can carry over benefits from month to month to create an emergency fund in case of a crisis (Doty, 1998).

Once a plan is chosen it is usually sent to a governing body for approval. However, in some instances the coach is in charge of tracking and approving spending as it happens. Self-Directed Care programs are voluntary and include personal healthcare accounts which can be used to purchase services which help participants obtain recovery goals. Self-Directed Care



programs starts with an individualized/person centered recovery planning process which is followed by individualized budgeting, consumer and provider education, and financial management services. Oversight and quality improvement services are available throughout the process. Supportive advocacy through coaches/brokers are also present and help provide assistance from start to finish, including participant safety planning.

Self-directed care creates a market-based system, which is demand driven rather than supply driven. Supply driven systems favor the agencies that provide services rather than the consumer because the consumer does not have many options and therefore must “patronize providers that receive funding from the State to serve them” (Haines & Spauding-Givens, 2007 p. 8). In other words, agency providers receive funding from States and then provide a pre-selected number of services which consumers must then choose from. However, as an alternative to this model, participants within a SDC program can purchase the services they want from both the public and the private mental health systems. This provides participants with a wider range of services. Individuals with only Medicaid coverage often are very limited in their choices because many providers do not accept Medicaid due to its low reimbursement rate and because of the large amount of paperwork involved (Hendry, 2008). A SDC program helps Medicaid recipients overcome the limitation of a narrow selection of services being provided.

Responsibility for the prudent utilization of public funds is placed on the individual receiving the funds. This expresses confidence that the individual knows him/herself best and therefore, knows how best to utilize the available resources. While support is provided in ensuring that the money is dispersed evenly throughout the year, the responsibility ultimately falls on the participant to choose how and where the money will be spent. Although funding is not dependent on success, in SDC focus on personal responsibility is a paradigm shift away from

denying self-direction toward that of seeking ways in which individuals can be supported in succeeding in self-direction (SAMHSA, 2004). In order to accomplish this, Self-Directed Care programs must include advance directives, use of fiscal intermediaries, and other means to ensure that an individual's choices are respected (Stefan, 2004).

Ensuring that new programs do not cost more than programs currently in place is an important factor in developing new services (SAMHSA, 2004). Maintaining budget neutrality is a basic criterion for the SDC waivers currently being provided by the federal government in areas such as long-term care. The majority of the pilot programs that have implemented SDC indicate that the cost of services is approximately cost equivalent or cost less than the cost of traditional mental health treatments (SAMHSA, 2004).

#### **Elements of Self-Directed Care in the MY VOICE program.**

The MY VOICE program is conceptualized as a precursor to a fully operational SDC program in Kansas. However, currently the Kansas mental health system does not enable individualized budgets to be attached to the MY VOICE program, limiting it to the planning stage of SDC. This means that while the MY VOICE program does not include the budgeting portion of SDC it does borrow the concept of individualized/person-centered recovery planning. In particular, the recovery plan can contain goals that might not be included in a traditional treatment plan. In a way similar to SDC, the MY VOICE program provides participants a resource which helps them stay organized in their attempts to achieve some of their recovery goals outside of the traditional case-management interaction. If they so choose, participants can also bring their recovery plan to their case-manager advocate to obtain some of their goals through their regular treatment plan. Being able to strive for goals within and without of

traditional mental health care has the potential to expand the activities which participants view as possible which can lead toward recovery.

### **Empirical Support for Self-Directed Care.**

Self-directed care strategies have been utilized in aging/long-term care and with individuals with developmental or cognitive disabilities for over a decade in programs in Europe, Canada, and the U.S. (Alakeson, 2010). However, using SDC with individuals with psychiatric disorders is a relatively new development with only limited pilot projects thus far reported (Alakeson, 2008). Most programs have had fewer than 50 consumers participating with the largest program located in Florida serving over 400. A number of states have experimented with SDC pilot programs, including Florida, Maryland, Arkansas, Oregon, Massachusetts, Iowa, Michigan, Tennessee, Vermont, New Hampshire, Oklahoma, and Pennsylvania. These pilot programs vary from each other, and most have not published their results. Some states have only focused their mental health SDC efforts in the employment arena rather than on the full range of services consumers often require (see O'Brien, Ford, & Malloy, 2005 for a description of the employment focused studies).

Self-directed care services have been evaluated using a variety of outcomes. Outcomes studied include the amount of money spent out of individual accounts, where the money is spent, residential stability, re-hospitalization rates, levels of participant satisfaction, service utilization rates, and levels of community integration and interaction (Hall, 2007).

Studies of self-directed care within the context of aging and general healthcare report generally positive findings such as greater satisfaction with services (Doty, 2000) and care arrangements (Schore, Foster, & Phillips, 2007) when compared to controls. The quality of life of consumers has been reported by consumers as improving (Foster, Dale, & Brown, 2007). Very

few workers or consumers report being exploited (Shore et al., 2007) and participation in self-directed care programs has resulted in good health outcomes (Krahn & Drum, 2007; Simon-Rusinowitz, Mahoney, Loughlin, & Sadler, 2005) and participants usually receive more services (Dale et al., 2003; Foster et al., 2003). Fraudulent use of the cash benefit is reportedly rare (Shore et al., 2007). Most programs report budget neutrality or budget savings (Dale et al., 2003; Foster et al., 2003). While the outcomes of SDC programs in the aging and health contexts are encouraging, similar positive outcomes of SDC in the mental health context have not been studied.

*The Arkansas Cash and Counseling program (CC)* was evaluated using a randomized controlled trial which included aging and long term care, chronically disabled, and psychiatric disabled elders (Benjamin & Fennell, 2007; Dale et al., 2003). The data were later analyzed focusing specifically on individuals with psychiatric disabilities (Shen et al., 2008). Of the 1,266 members of the original RTC, 203 individuals were diagnosed with a psychiatric disability. All participants in the CC program were given a budget to hire personal caregivers (which could be family or friends) and purchase goods and services. Assessments were delivered at baseline and nine months follow up. Results of logistic regression indicated significantly higher odds that those in the treatment group would report that they were very satisfied with their caregiver, never felt neglected, and had greater satisfaction with the way they were spending their lives when compared to controls.

While the results of this RTC are encouraging there are several limitations to consider. The psychiatric diagnosis variable was dichotomized (yes/no), combining persons with psychiatric disabilities from low to high severity into one group. Given the range of perceptual distortions that are, by definition, part of mental illness, it is likely that persons with more severe

diagnoses would respond differently than those with less severe diagnoses. Further, diagnoses were based on the prior year's Medicaid claim records, excluding some persons from the sample if they had not made a Medicaid claim under that diagnosis within the study year. Random assignment to treatment and control groups is a strength of this research, tempered by the small ( $n=203$ ) and homogeneous (elderly) sample, thus limiting the analysis and findings (Shen et al., 2008).

*The Florida Self-Directed Care program* (Florida-SDC) published descriptive data from a pre-post evaluation where participants were allowed to spend budgets that amounted to the average per-capita cost of outpatient funded services the previous year (Cook et al., 2008). Individuals could spend their money on traditional mental health services or on any other community goods or services used to help the individual recover. The program employed recovery coaches to help participants “broker” or secure goods and services.

The evaluation used a simple pre-post design (no random assignment or control group) which followed 106 participants for the first 19 months of operation. Paired t-tests were conducted to determine outcomes before and after entry. On average, participants spent a significantly greater number of days in the community (versus inpatient or forensic settings). Participants also scored significantly higher on the Global Assessment of Functioning Scale than in the year before.

These results were augmented with qualitative data gleaned from interviews with participants ( $N=13$ ), which revealed high levels of satisfaction with service availability. In contrast, interviews with nonparticipants ( $N=8$ ) (defined as those who had expressed interest in the program but did not enroll) reported dissatisfaction because of their inability to obtain needed services. Cook et al. (2010) reported one “surprising” finding that, on average, participants spent

approximately one third of the funds they had been given to budget. As positive as the results of this pilot program are, design flaws limit its usefulness. For example, the study had no comparison group, no random assignment, had a small sample size, and was descriptive, making the findings less generalizable outside of Florida.

*The Texas Self-Directed Care program* (Texas-SDC) is currently collecting data for an RCT study where adults with psychiatric disabilities are randomly assigned to enter the Texas-SDC program or receive treatment as usual (Cook et al., 2010). Outcomes being assessed (but not yet reported) include changes in health/symptoms, wellbeing/quality of life, hopefulness, empowerment, satisfaction, service use, service costs, and economic indicators. The Texas-SDC program is similar to the Florida-SDC program with the major exception that consumers have been involved in a Participatory Action Research (PAR) process from project start to finish (Cook et al., 2010). The Texas-SDC program participants receive \$4,000 to \$7,000 per year to budget and spend on goods and services which facilitate recovery. Support brokers ("SDC advisors") are available to assist individuals from the beginning to the end of the SDC process.

To date only demographic characteristics and initial budgeting information is available for the first 20 individuals enrolled in the study. Once completed, this research will be important for SDC research in mental health because of the attention paid to rigorous design and important outcomes (such as empowerment, quality of life, and economic indicators). However, one limitation is that participants are only allowed to spend their budgets within a designated network of providers. This may limit the goods and services which participants can purchase.

*The Oregon Empowerment Initiatives Brokerage* (EIB) project was a small pilot program with only 25 participants (Sullivan, 2006). The EIB intervention included person-centered planning, a support group, budgeting assistance, and assistance with plan implementation. The

study was of pre-post design without random assignment or controls. Outcomes were assessed at baseline and every three months for one year. The results indicated increases in consumer satisfaction with the plan, level of goal achievement, increased independence, and capacity to self-define (Sullivan, 2006). Increases in education involvement, employment, and independent living were also shown. However, the results from the survey were presented descriptively with no corresponding statistical tests or analyses. Therefore, the significance of the results could not be assessed. In addition there were several other limitations, namely the lack of randomization, lack of comparison group, and small sample size. While conceptually important constructs were assessed, very few conclusions can be gleaned from the results.

*The U.K. Person-Centered Thinking and Personal Budgets* program reported on the use of self-directed personal budgets in three early intervention teams in the North West of England. Using a narrative qualitative methodology, seven consumers were interviewed individually on two occasions and two additional focus groups were held (Coyle, 2011). Results indicated that the SDC tools were helpful to staff by enabling them to gain new insights about what was truly important for consumers. Consumers reported a belief that the personal budgets enhanced their recovery. More research is underway to study this specific SDC program which has not yet been reported.

Of the five empirical studies which directly explored SDC in mental health, only one was a randomized controlled trial (Shen et al., 2008) and it is important to note that this trial was conducted on an elderly population in a long-term care context, limiting the generalizability of the findings. Of the four descriptive studies, two were pre-post in design and two included at least some qualitative data. All of the descriptive studies have limitations which include sampling, the lack of randomization, lack of comparison group, and small sample sizes. At this

point in time there is very little qualitative or quantitative research available which explores SDC in the mental health context. The studies which are available lack rigor and are equivocal in their results.

The primary variables assessed in these studies focused on satisfaction with services, relationship with the providers, services utilized, and cost of the program. While empowerment and self-determination have been used as concepts for SDC intervention development (e.g. Cook et al., 2010), little attention has been given to using these concepts as outcome measures. In addition, none of the five studies examined reported that the intervention assessed for consumer strengths or was anchored in strengths-based practice. On the other hand, all five studies reported that the SDC program under examination was geared toward helping individuals recover, however none of them used an assessment to determine if an individual's stage of recovery changed over time.

### **The Shared-Decision Making Model.**

Shared-decision making (SDM) is a model of collaborative treatment developed in medical settings and recently applied in mental health care, particularly within the context of consumer-prescriber interactions (Drake, Deegan, & Rapp, 2010). Given the expressed desires of consumers (Deegan, 2007) and the positive results found with its use in other areas of mental health (Swift & Callahan, 2009) and generalized healthcare (Curtis, Wells, Penny, Sushmita et al., 2010), SDM holds promise for enhanced mental health treatment planning by potentially increasing treatment adherence, engagement and self-determination.

Shared-decision making involves at least two people and must include three distinct components: (1) information and preparation for making a decision, (2) the interactive process of discussing and generating a shared decision, and (3) systematic opportunities to review and



revise decisions after they are made (Curtis et al., 2010). In other words, SDM could be defined as decisions that are shared between treatment providers and consumers which are informed by the best evidence available and by the specific needs, preferences, and values of the consumer (SAMHSA, 2010).

It is important to emphasize that a judgment of what is a *good* shared decision is based on more than just the outcome of the decision; it is one that is made deliberately and thoughtfully, with accurate information, and which is consistent with the consumer's values (O'Connor, Jacobson, & Stacy, 2002; Virancearu, Cooper, & Ring, 2009). Shared-Decision Making allows customization based on consumers' needs and wants and therefore increases consumer control in treatment. When SDM is conducted correctly there is shared knowledge and free flow of information. To help ensure that information is free flowing, emphasis is placed on the use of decision aids and technological tools that facilitate accurate information dispersal and decision making processes (Drake, Deegan, & Rapp, 2010). Decision aids are defined as decision support interventions that:

...help people think about choices they face...describe where and why [the] choice exists...provide information about options, including, where reasonable, the option of taking no action. These interventions aim to help people to deliberate, independently or in collaboration with others, about options, by considering relevant attributes, to help them forecast how they might feel about short, intermediate and long-term outcomes which have relevant consequences, they support the process of constructing preferences and eventual decision making, appropriate to their individual situation. (Elwyn, Frosch, Volandes, Edwards, & Montori, 2009, p.5)

Consumers often decide not to follow their treatment plans or take their medications as prescribed if they experience an internal conflict between their personal values and what their treatment plans say they must do (Deegan, 2005). A classic example of this decisional uncertainty is illustrated when a consumer must choose between taking a medication that reduces symptoms but also reduces sexual performance. Shared-decision making helps align medication

prescriptions and treatment plans with consumer recovery goals, which in turn helps to increase congruence with consumer values (Malm et al., 2003) and increase engagement in services (Swanson et al., 2007). Shared-decision making holds promise for equalizing power imbalances (Drake, Deegan, & Rapp, 2010), increasing consumer choice (Roe et al., 2009), increasing engagement and treatment adherence (Swanson et al., 2007; Joosten et al., 2008) and ultimately increasing recovery for individuals with psychiatric disabilities.

### **Elements of Shared-Decision Making in the MY VOICE program.**

Shared-Decision Making contains several components which MY VOICE incorporates. The first is a focus on facilitating a decision making process. The MY VOICE program is intended to help participants make decisions about the values and goals that are important to them. Similar to SDM where a good decision is defined as one that is based on client values and preferences (O'Connor et al., 2002) the MY VOICE is designed to help consumers identify the values they hold dear and link them with what they decide their ultimate recovery goals are. In addition, while not tested in the present study, the MY VOICE program provides consumers with the opportunity to create their own personal recovery plan and list their personal strengths which can be used as a personal decision aid in their advocacy with other treatment providers. For example, a participant could bring their personal recovery plan to their case-manager and compare it to their treatment plan. This may begin a dialogue about the consistencies and discrepancies between the two plans which may in turn lead to a shared-decision making process regarding the future course of treatment. In this case, participants are making more informed decisions about their care which is an additional component of shared-decision making.

### **Empirical Support for Shared-Decision Making.**

As with self-directed care, some of the research in shared decision making has occurred in broader contexts than mental health. A systematic review of decision making in general healthcare indicates that people's preferences for involvement in decision making vary with age, educational status, severity of disorder, and ethnic or cultural differences, and also may fluctuate over time (Coulter and Ellis, 2006). Further, despite this variability, when SDM processes are used in general healthcare, individuals are often more satisfied with the decisions that are made and the process used in making the decision when compared to individuals who do not participate in SDM (e.g. Lewin et al. 2001; Mandelblatt et al., 2006). Specific to mental health, there have been at least 25 quantitative studies conducted as well as many qualitative studies. An initial review of some of the quantitative studies is conducted followed by a description of some of the descriptive/qualitative studies available.

A meta-analysis geared specifically toward analyzing SDM in mental health was conducted by the Cochrane Collaboration (Duncan, Best, & Hagen, 2010). Of the 197 SDM studies assessed for inclusion in the meta-analysis, 25 met criteria for full text review and only 2 met criteria for ultimate inclusion. Studies were excluded from the analysis if they were descriptive, qualitative, lacked a comparison group, lacked randomization, or included SDM as part of a larger intervention making it impossible to determine the effects of SDM alone. The two studies meeting inclusion criteria were authored by Hamann et al. (2006, 2007), and Loh, Simon, Wills, Kriston, Niebling, & Harter (2007) and both were randomized controlled trials with sample sizes of 113 and 405 consumers, respectively. Hamann's sample consisted primarily of consumers diagnosed with schizophrenia or schizoaffective disorders and Loh's sample consisted primarily of consumers diagnosed with depression. Duncan et al. (2010) reported that,

based on their analysis of Hamann and Loh's studies, SDM intervention increased consumer satisfaction in the short term and provider facilitation of consumer involvement in decision making was increased by the intervention. Duncan et al. reported that while there are many studies of SDM specific to mental health available, very few of them are rigorous enough to be included in the meta-analyses, thus limiting the positive conclusions about effectiveness.

Some additional quantitative studies on SDM include Priebe et al.'s (2007) study. Priebe et al. (2007) conducted a randomized controlled trial of SDM as a structured dialogue model designed to help providers (n = 134) elicit and focus on individuals' views. After 12 months, individual participants had better subjective quality of life, fewer unmet needs, and higher treatment satisfaction than did controls. Priebe et al. (2007) noted that their sample may not have been generalizable to other mental health service settings and that because they could not mask from consumers who their providers were, consumers may have reported positive effects in order to please their clinicians.

In 2004, Van Os et al. conducted a randomized controlled trial of SDM with 134 participants by using a two-way communication checklist. The results indicated that in comparison to control groups a simple intervention to aid people in discussion of their needs resulted in improved communication and changes in treatment. In addition, having the consumer set the agenda for discussing treatment needs improved the quality of consumer-doctor communication and focusing on simple, non-pharmacological interventions may have considerable value in the treatment of consumers with multiple needs. However, Van Os, et al. (2004) noted that the study may have had challenges with regard to masking. For example, there was a possibility that the clinicians' behavior changed because they wanted to show that the

intervention worked. They reported that consumers might have reported positive experiences with the clinician for similar reasons.

Most studies of SDM in mental health to date have been conducted within prescriber-consumer interactions. An important study by Woltmann et al. (2011) reported on a randomized controlled trial of SDM within case-management. Results were reported indicating that (1) those in the intervention group were more satisfied with the planning process, (2) those in the intervention group had greater recall of their plans, and (3) there was increased case manager awareness of client concerns. Another important outcome from this study was the determination that it is possible for consumers to write their own treatment plans using a technological decision-making aid.

Most of the studies conducted on SDM within the mental health field have been either qualitative or descriptive. Qualitative and descriptive studies illustrate much of the current need by consumers for SDM in mental health, for instance, it has been reported that individuals with psychiatric disorders have a greater desire to be involved with decision making about their treatment than do people receiving general health care (Hamann et al. 2005, 2007). The majority of people with mental illness express a desire to participate in making decisions regarding medications and hospitalizations (Adams 2007, Hamann, 2005, Noble, 2004, Oneal, 2008) and believe that their involvement in decision making in treatment is too passive (Adams, 2007, Deegan, 2007, Oneal, 2008). Shared-decision making can also qualitatively increase engagement (e.g. Kreyenbuhl, Nossel, & Dixon, 2009). However, consumers have reported that in order for shared-decision making to be most effective they would prefer that the information being provided be easily accessible and easy to use (Stein, Kogan, Essock, & Fudurich, 2009). For instance, Adams (2006) found that while the majority of consumers expressed comfort in

using a SDM computer, their acceptance of it related to the tools ease of use; if paper was easier they preferred paper; if a computer was easier they preferred the computer.

Qualitatively, individuals who participate in treatment decision making appear to be satisfied with their treatment providers and the services they receive (Swanson, Bastani, Rubenstein, Meredith, & Ford, 2007). Lack of informed involvement by consumers may contribute to reduced follow-through (adherence) with treatment decisions – including psychiatric medications (Roe et al., 2009).

Lown, Hanson, and Clark (2008) explored the interpersonal qualities of SDM in detail and found that both consumers and physicians identified six categories of paired physician/patient themes which fluctuated by context. Participants described a dynamic process in which patients and physicians influence each other throughout shared decision making. This study is augmented by research by LeBlanc, Kenny, O'Connor, and Legere (2009) which found that during the dynamic SDM process if one partner in the shared decision felt uninformed it lead to decisional uncertainty (which can affect treatment adherence or provider coercion). The results indicated that the more unclear a person was of their own goals, the more they perceive that an ineffective choice had been made, and the more both physicians and consumers experience personal uncertainty (lack of confidence in the decision made). They also indicated that the more informed consumers or providers felt, the more both physicians and patients experienced personal certainty (confidence in the decision made) (LeBlanc, Kenny, O'Connor, & Legere, 2009).

The values clarification and decisional conflict issues described by Leblanc (2009) are common experiences which interventions like CommonGround© are meant to help address (Deegan, 2007, 2010). CommonGround© is a computerized decision aid program which helps

consumers make decisions and advocate for themselves during psychiatric visits. Qualitative research on CommonGround© indicates that the majority of consumers will use CommonGround© if there are peer supporters available (Deegan, 2007) and that there are many activation points within CommonGround© that can be utilized to increase engagement and participation by consumers in SDM with providers (Goscha, 2010).

Qualitative researchers have analyzed consumer response themes that seem to imply that the quality and adherence to SDM treatment programs are increased if providers attempt to make the shared-decisions relevant to the values, non-medication needs and long-term goals of the consumer (e.g Goscha, 2010; Malm, 2003; Mahone, 2008). In particular, qualitative SDM research has noted the importance of non-medication goals and strategies which help consumers with resilience and recovery (Deegan, 2005).

Woltmann (2010) conducted a qualitative study of SDM specific to case-management. Most consumers preferred a SDM process but when asked what “shared” meant, consumers “describe[d] a two-step process which first prioritize[d] autonomy, and if that is not possible, defer[red] to case-managers’ judgment” (p.29). This suggests that extra care needs to be taken in the case-management context because consumers may consciously decide to verbally agree with their case-manager, but remain silent about what they would really prefer (Woltmann & Whitley, 2010).

Similar to the self-directed care literature, SDM has not included a focus on consumer strengths when designing interventions or studying interactions. In addition, other important underlying theoretical constructs have not been measured as outcomes, such as assessing for increased consumer perception of recovery, empowerment, or self-determination.

The large majority of studies conducted on SDM in mental health have used descriptive or qualitative methodologies while very few have used randomized controlled designs. Most studies have limitations such as lack of randomization, lack of comparison group, and small sample sizes. The studies of SDM in mental health have primarily focused on medication management (e.g. LeBlanc, Kenny, O'Connor, & Legere, 2009; Mahone, 2008; Priebe, McCabe, Bullenkamp, Hansson, et al., 2007; Van Os, Altamura, Bobes, Gerlach, et al., 2004) and only two have focused on case-management (Woltmann & Whitley, 2010; Woltmann, Wilkniss, Teachout, McHugo, & Drake, 2011). Studies of the application of SDM in other areas of mental health, beyond the prescriber-consumer medication interaction, are needed. Additional areas of SDM study might include interactions with case-managers, clinicians, and peer support workers.

### **Research on Electronic Decision Support Interventions in Mental Health**

The MY VOICE program is an electronic decision support intervention (EDSI). Electronic decision support interventions can be viewed as either providing information and guiding decisions for either clinicians or for consumers. In the case of clinicians, electronic decision support systems apply an electronic knowledge base to entered individual consumer information which leads to suggestions for clinical care. In a systematic review of the available provider-based decision support interventions 59 trials were evaluated. The results were mixed indicating that no firm conclusions could be made regarding whether provider centered electronic decision support interventions improve consumer outcomes (Hemens, et al., 2011). This is intuitive as provider centered decision support interventions may support a paternalistic care paradigm by providing suggestions on treatment without ensuring consumer involvement.

Consumer focused EDSI's on the other hand are relatively new and are focused on helping consumers make decisions either during or prior to interactions with providers (Elwyn,



Frosch, Volandes, Edwards & Montori, 2010). These interventions help consumers clarify their values, identify treatment preferences, and help them advocate for themselves during shared-decisions with providers. Therefore, EDSIs hold more potential to engage consumers in treatment decisions and in promoting self-direction. Research on EDSIs is in its infancy in the mental health arena, with only a few studies available. Before reviewing the literature it is important to differentiate EDSIs from other forms of decisional support for consumers.

While definitions overlap somewhat in the literature, for the purposes of clarity in this review decisional supports can be conceptually divided into three categories: Decision aids, decisional coaching, and electronic decision support interventions. Decision aids, decisional coaching, and EDSIs can be defined as structures meant to help individuals make informed decisions about their health care. In the case of decision aids, this structure can take the form of brochures, pen and paper exercises, or simple electronic information. Decisional coaching on the other hand takes the form of personal coaches who help consumers walk through decision making processes through an interpersonal interaction. Electronic decision support interventions usually are more complex technological software programs meant to help individuals walk through a decision making process. Decision aids, coaching, and EDSIs can be used separately or in conjunction with each other. For instance, the CommonGround© decision support center developed by Deegan (2007) combines an EDSI program with decision aids and coaching provided by peer support workers.

Within the SDC and SDM models there continues to be a lack of decisional aids, EDSIs, and coaching available. For instance, while the majority of SDC programs include coaches or brokers which help with decision making, there are very few decisional aids or EDSIs developed and available. The Substance Abuse and Mental Health Services Administration (2010) even

noted that within SDC programs many consumers do not necessarily know what their options are. As a result, consumers may often just choose to follow recommendations that they are familiar with, rather than those that may be more appropriate or beneficial (SAMHSA, 2010). This means that within SDC programs extra-efforts to ensure that consumers are informed of all of their options and the potential consequences of their decisions need to be made; and decision aids and EDSIs need to be developed. Conversely, in the case of SDM there are more decision aids available (although more are still needed). However, there are only a few SDM programs that include a decisional coach. Taken together, it is apparent that shared-decision making and self-directed care decision aids and other electronic decision support technologies are desperately needed (Drake & Deegan, 2009).

Decisional aids and EDSIs are meant to provide the consumer with (1) factual information about the evidence based practices, including options and outcomes; (2) clarification of the options and outcomes based on the consumers values; and (3) communication and deliberation guidelines for expressing the consumer's values and informed choices to the provider (O'Connor et al., 2007). Some researchers indicate that decisional support interventions are be used to provide clinical information in situations where equally valid options of care are available (Elwyn, Frosch, Vollandes, Edwards, & Montori, 2009). These are situations where the costs and consequences of several options are approximately equivalent. However, others argue that even in situations where costs and consequences of several options are not equivalent, consumers values and preferences should be taken into consideration (Peterson, 2012); particularly because if consumer preferences are included in treatment there is an increased likelihood that consumers will identify benefits from care and remain engaged in treatment in general (Swift & Callahan, 2010). Decision aids should do more than present

consumers with risk-adjusted information. “Decision aids [should] also include values clarification exercises through which people grapple with questions of how treatment might affect quality of life” (Drake, Deegan, & Rapp, 2010, p. 8).

In general healthcare, EDSIs have been used to help patients manage their own electronic records. One study of 192 individuals found that the majority of patients in general healthcare were highly satisfied with an EDSI program and the associated process of shared decision making (Hirsch, Keller, Krones, & Donner-Banzhoff, 2011). Two-thirds of the individuals sampled wanted to use the EDSI again and 80.7 percent of the sample said that they implemented the decision, independent of gender and education. The authors of the study reported that based on their results EDSIs can be used for a wide range of populations with a wide range of individual characteristics.

Despite the positive findings for consumer-centered EDSI in general healthcare, only a few EDSIs have been developed specifically for individuals with psychiatric disabilities. One study on an EDSI geared specifically for individuals with a psychiatric disability to increase motivation for smoking cessation used a quasi-experimental design of 41 individuals to determine if evidence-based smoking cessation behaviors increased through use of the EDSC program (Brunette, Ferron, McHugo, Davis, Devitt, Wilkness, & Drake, 2011). Participants who used the decision support system were significantly more likely to show behavioral motivation to quit smoking. In addition, using the EDSI increased by a factor of 2.97, or about 300%, the expected number of ways that a participant showed motivation.

In 2011, Woltmann et al. conducted a cluster randomized trial of an EDSI in a mental health case-management context with 80 consumers at three urban community mental health centers (Woltmann, et al., 2011). Compared with consumers in the control group, those in the

intervention group had significantly greater recall of their care plans three days after the planning session. The study demonstrated that consumers can build their own care plans and negotiate and revise them with their case managers using an EDSI.

An additional EDSI has been developed to help consumers make shared-decisions and advocate for themselves in the visit with their medication prescriber (Deegan, 2007). This EDSI has primarily been evaluated qualitatively. Results of these studies report that consumers indicate that the program helps make the prescriber interaction more efficient (Deegan, Rapp, Holter, & Riefer, 2008), empowers clients to be more involved in their treatment related decisions (Deegan et al., 2008) creates activation points that engage consumers in their treatment (Goscha, 2010), helps resolve decision uncertainty and supports personal medicine (activities beyond pill medications that support recovery) (Deegan, 2005; 2007), provides peer support workers with a strong role in care, and supports shared-decisions (Deegan, 2010). A randomized controlled trial of the Deegan EDSI program is currently underway.

Adams (2007) conducted a descriptive survey of 82 outpatient consumers and 30 self-help mental health consumers regarding their opinions and experiences with EDSIs. Adams found that EDSIs geared toward medication values clarification were an inexpensive way to promote shared decision making and were feasible to use with the majority of mental health consumers (Adams, 2007). Perceived ease of use was the primary indicator of whether or not consumers preferred to use an EDSI, although this was not related to actual computer skill ability. On the other hand over 25% of the sample expressed that they felt an EDSI might enhance their desire to participate in psychiatric treatment decision making.

The research on electronic decision support centers in mental health is very new with most experimental studies only occurring within the past three years. While the initial research

in mental health is encouraging, it is apparent that, in general, more EDSI programs need to be developed and studied.

### **Critical Analysis**

Examination of the theoretical and empirical literature for SDC and SDM reveal several limitations that need to be addressed in future research. At the outset, many of the elements of SDC and SDM were championed by consumers as a means to create a change toward realizing equalized relationships in the mental health system (Nerney, 2003). By including empowering structures that facilitate greater control over treatment, SDC and SDM models are consistent with anti-oppressive approaches to practice. However, some argue that models like SDC and SDM do not go far enough to address medical model definitions of mental illness (e.g. Thompson, 2006) and that they may conceal some political aims. For instance, one of the primary differences between Shared-Decision Making and Self-Directed Care is the level of autonomy provided in making decisions. In SDC individuals are more autonomous (although they still have support and oversight) while in SDM decisions are shared between the provider and the consumer. Some consumers have mentioned that they felt that SDM was a step backward from being fully autonomous and that, while decisions may be shared, the decisions still occurred within a system that labels them as having a disease (e.g. James, 2008).

In addition, Spaulding-Givens (2011) argues that while self-directed care includes elements of self-determination and empowerment, it was accepted by federal authorities during a conservative social welfare environment. She contends that the endorsement of SDC by authorities may be suspect because political empowerment rhetoric often hides the covert aim of limiting state funded services. Therefore, while the efforts of the consumer/survivor movement to encourage models like SDC and SDM are admirable, acceptance of these models should not

be made uncritically. It may be that SDC and SDM models don't fully address medical model definitions of mental illness and may be laden with less transparent political aims meant to reduce services to those who may need them. For instance, a basic assumption of the SDC model is that market forces will drive the development of adequate access to the services participants will want to purchase. However, in the world of publicly funded human services this assumption is not always viable. Some programs may have waiting lists, and other services may not exist in close enough proximity to the individuals who need them. There is concern that providers and services which are demanded by clients will not develop at an acceptable rate, creating a period of poor service provision and lack of access. In addition, consumer oriented features in health plans can sometimes mask real reductions in benefits and transparency that is often difficult to ascertain. For instance, costs of medical procedures and prescriptions are not always clear (Dougherty, 2007). It will be important for future studies to determine whether SDC and SDM truly help individual's self-identify increases in empowerment, self-determination, and recovery, and whether they hide real reductions in services. If there is a reduction in services there may be a danger that some services under the guise of recovery actually force individuals out of services and into jails or the street.

In addition, while a focus on strengths has been identified as an important component of an empowerment approach (Greene, Lee and Hoffpauir, 2005) and empowerment is an important theory underlying both SDC and SDM, little research has been conducted using a focus on strengths as an underlying perspective for either model. Neither SDC nor SDM include a clear means for identifying and then using strengths to meet recovery goals. Adding such an element may benefit both approaches.

Many of the existing SDC and SDM studies are inadequate due to small sample sizes and convenience sampling. This may be because many of these studies were conducted early in program development and implementation (e.g. Cook et al., 2008; Cook et al., 2010; Hall, 2007; Sullivan, 2006; Teague & Boaz, 2003). Most of the studies have also been characterized as descriptive or quasi-experimental, lacking comparison groups. This means that the majority of the studies failed to control for many threats to internal validity such as history, maturation and testing. When comparison groups were utilized the majority did not include random assignment reducing confidence that the findings were directly related to program participation.

### **Description of the MY VOICE Program**

The MY VOICE: Strengths-based and Self-Directed Recovery program is an EDSI which guides consumers through a self-directed recovery planning process. Person centered recovery planning is an essential first step in a self-directed care program (Coakley, 2009). The MY VOICE EDSI merges elements from both the Self-Directed Care and Shared-Decision Making models. From SDC, the MY VOICE program borrows the concepts of informed self-directed assessment and determining how and by whom consumer needs should be met. From SDM, MY VOICE borrows a focus on technological decision aids which help individuals increase their voice in treatment and make informed decisions.

In addition, consistent with the strengths perspective, individual strengths are assessed in the MY VOICE program and paired with identified recovery goals. The program then assists individuals in planning initial steps toward reaching their goals. Individuals can return to the program from any internet connection and update their plan as often as they would like. The plan includes self-identified steps consumers can take to begin or continue their recovery journey. Consumers can then print out a list of their strengths and/or their initial recovery plan

and take them to whomever they want. They can also email their list of strengths or their recovery plan to whomever they would like. Consumers can go through the MY VOICE process as many times as they would like.

Once consumers have gone through the program once and have received a login name and password they can choose from the following options: (1) fill out an optional strengths assessment, (2) identify values or elements of their life that motivate them or are important to them and provide them purpose (e.g. family, hard work, nature, etc.), (3) identify additional strengths and resources, (4) identify goals, (5) rate the importance and their confidence in their ability to obtain the identified goals, (6) prioritize their top three goals, (7) link strengths and motivators to their goals, (8) identify initial small steps, and (10) print or email their plan/strengths. Trained peer support workers are on hand to help consumers walk through this process the first time. Peer support workers are also available to field phone calls by consumers if they would like help with the program later.

The first task of the MY VOICE program is to help participants identify values in their lives that motivate them, such as being a good parent, or being able to enjoy nature. These values are used later in the program to add motivation and purpose for obtaining their identified goals. Next, participants begin entering strengths that can help participants overcome barriers and obtain their goals. For instance, strengths can be skills, resources, assets, or qualities. Once strengths are entered they can be accessed and linked to specific goals. The third task is to start developing goals. Goals are identified within the following domains: Home/Daily Living, Health/Wellness, Spirituality/Culture, Supportive Relationships, Spirituality/Culture, Leisure/Recreation, Employment, Education, and Assets/Finances/Insurance. Goals do not have



to be chosen for all of these domains. Multiple goals could be identified in one domain and not in another.

Individuals can develop as many goals as they like. Once goals are developed participants have the option to add additional strengths which they may have thought of while thinking about a particular recovery goal. Then participants rate how important they view the recovery goals they have developed and how confident they are in their ability to achieve their recovery goal. Once the recovery goals have been rated participants can use their scores as a means to help prioritize their goals. Participants use this information to help them choose their top three recovery goals. Once they have prioritized their top three goals participants create declarations called recovery statements. Recovery statements are defined as linking a previously identified purpose or value and linking it to their goal. For instance a consumer might have earlier identified that they value providing for their family. Later they might have identified the goal of getting a job. They would link the value with the goal and develop a recovery statement which states “I want to get a job in order to provide for my family”. Following the pattern of linking previously identified values to an identified goal, participants in the MY VOICE program develop a recovery statement for each of their top three identified recovery goals.

After the recovery statements have been developed consumers have the opportunity to identify from their master list of strengths (which has been being getting longer over time) all of the strengths that they believe may help them achieve their prioritized top three recovery goals. In the final section of the program, participants are presented with their identified recovery statements along with a list of the strengths that consumers believe will help them achieve their

recovery goals. Consumers are then prompted to come up with two or three small tasks that will help move them closer to their overarching recovery goals.

After the MY VOICE program has been completed the first time, consumers do not have to complete the whole program again unless they want to. Consumers can choose to jump to the end of the program to access their tasks and indicate whether or not they have completed them, add or delete new tasks, or simply add an additional goal once a goal is completed.

While conceptualized as a SDC program, MY VOICE incorporates elements from both SDC and SDM. From SDC, MY VOICE borrows the concepts of informed self-assessment and determining how and by whom consumer needs should be met. From SDM, MY VOICE borrows a focus on helping people make decisions/clarify values, the development of technological decision aids which help individuals increase their voice in treatment, and helping individuals make informed decisions. While the Kansas mental health system does not yet enable individualized budgets to be attached to the MY VOICE program, limiting it to the planning stage of SDC, the development of the MY VOICE program provides an opportunity to expand the breadth of the inquiry in SDC-SDM research.

It was anticipated that the MY VOICE program would facilitate self-determination, empowerment and progress in recovery by providing a means for individuals to conduct a meaningful self-directed self-assessment of their strengths, identify their personal recovery goals, link their strengths to their goals, and identify initial tasks toward goal completion. The goals and tasks are completely self-directed and can include goals that may not be included in traditional mental health case-management treatment.

## Research Questions

The purpose of this pilot study is to determine what characteristics predict completion of the MY VOICE program and to test the theory that participation in the self-directed MY VOICE EDSI program may lead to increases in consumer self-identified empowerment, self-determination and recovery. Specifically, this study tests the relationship between participation in MY VOICE: Strengths-based and Self-Directed Recovery program with scores on The Empowerment Scale (Rogers, Ralph, & Salzer, 2010), the Self-Determination Scale (Sheldon, Ryan, & Reis, 1996) and the Self-Identified Stage of Recovery Scale (SIS-R) (Andresen, Caputi, & Oades, 2010), while controlling for baseline scores on these measures.

A randomized controlled waitlist design was employed to answer the following research questions:

- (1) What participant characteristics predict completion of the MY VOICE program?
- (2) Do consumers who use the program have higher posttest scores on the outcome variables of self-appraised empowerment, self-determination, and progress in recovery than those in the control group?
- (3) For those who complete the MY VOICE program, are there higher posttest scores on the outcome variables of self-appraised empowerment, self-determination, and progress in recovery?
- (4) Do the number of completed tasks in the MY VOICE program relate to higher posttest scores on the outcome variables of self-appraised empowerment, self-determination and progress in recovery?

It was hypothesized that: (1) some demographics characteristics may predict MY VOICE completion, (2) those who use the MY VOICE program will show greater increases in measures of self-reported empowerment, self-determination, and progress in recovery than those in the control group, (3) completion of the MY VOICE program will predict increases in self-reported empowerment, self-determination and progress in recovery, and (4) the number of tasks consumers complete will predict increases in self-reported empowerment, self-determination, and progress in recovery.

## **Chapter 3: Methodology**

### **Participants**

The MY VOICE computer program was implemented at Socialization, Interdependence, Development, and Empowerment (SIDE), an independent non-profit, multi-service, consumer run organization (CRO) located in an urban area of Kansas City, KS. It provides drop-in services as well as structured peer-support, recovery and education groups, employment assistance, exercise groups, art expression, and social opportunities. The governing board and employees of SIDE are all mental health consumers. The agency provides services to approximately 350 adult individuals with psychiatric disabilities in Wyandotte County, Kansas. Table 1 describes the demographic characteristics of those who participated in the study. The large majority of participants identified having a diagnosis of schizophrenia, bipolar, or major depression. If the participant identified that they had more than one psychiatric diagnosis, they were asked to indicate which diagnosis was primary. Most participants were African American, were receiving disability payments, and were receiving services from the local community mental health center. Of the 110 participants 58 were male and 52 were female, the mean age was 46 with a standard deviation of 10.8, and the mean level of symptom severity was 6.02, measured on a scale from 1 to 10, with a standard deviation of 2.33. Table 1 describes additional demographic characteristics of the sample.

Table 1

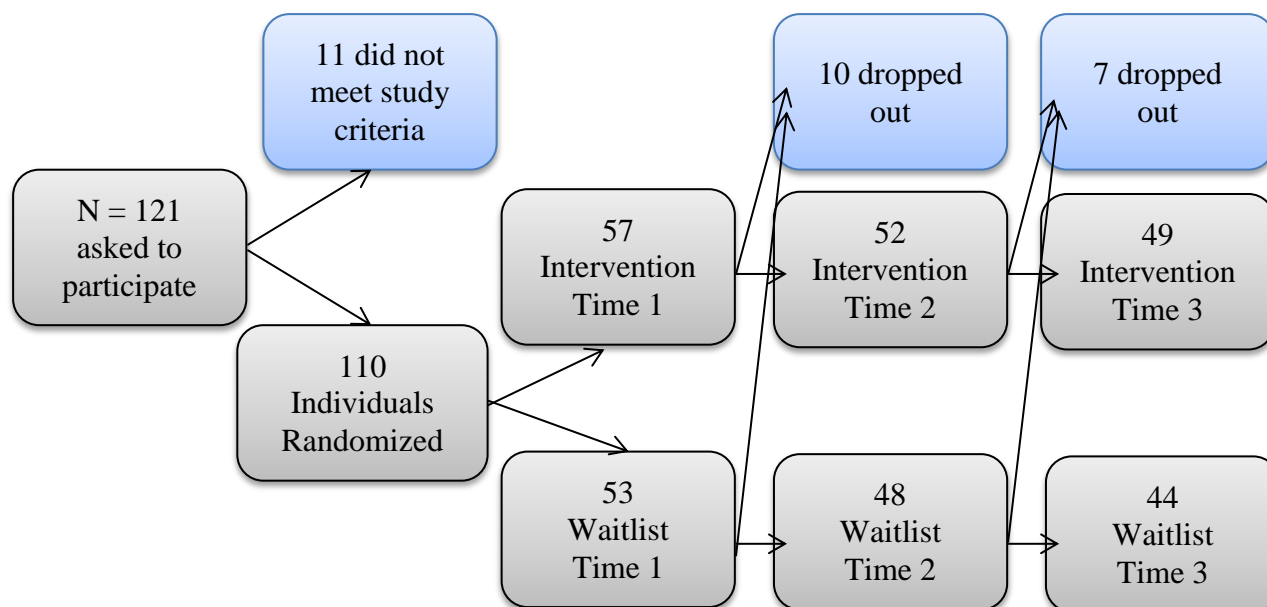
*Demographic characteristics of participants*

<b>Item</b>	<b>Participants</b>
<b>Diagnosis</b>	
a) Schizophrenia	a) n = 52
b) Bipolar	b) n = 32
c) Major Depression	c) n = 21
d) Other	d) n = 5
<b>Race/Ethnicity</b>	
a) Native American	a) n = 7
b) African American	b) n = 75
c) Caucasian	c) n = 26
d) Hispanic	d) n = 2
<b>Length of Time Attending Peer Center</b>	
a) 1 yr or less	a) n = 50
b) Over a year	b) n = 60
<b>Often Attended Peer Center</b>	
a) More than once per month	a) n = 53
b) Once per month or less	b) n = 57
<b>Education Level</b>	
a) HS equiv or below	a) n = 60
b) Some college or higher	b) n = 50
<b>Employment Status</b>	
a) Social Security	a) n = 61
b) Unemployed	b) n = 33
c) Part-time	c) n = 12
d) Fulltime	d) n = 4
<b>Insurance</b>	
a) Private	a) n = 2
b) Medicare/Medicaid	b) n = 84
c) No Insurance	c) n = 23
<b>Hospitalization</b>	
a) Hospitalized past year	a) n = 22
b) Not Hospitalized past year	b) n = 87
<b>Computer Ability</b>	
a) Poor	a) n = 50
b) Good	b) n = 60
<b>Computer Use</b>	
a) Never Used	a) n = 15
b) Used Rarely	b) n = 32
c) Used Sometimes	c) n = 25
d) Used Often	d) n = 37
<b>CommonGround© Use</b>	
a) Used	a) n = 37
b) Never Used	b) n = 72
<b>CMH Services</b>	
a) Receive Services	a) n = 93
b) Don't Receive Services	b) n = 17

One hundred and ten individuals were recruited into the study, 53 to the waitlist control group and 57 to the intervention group. Figure 1 illustrates dropout of participants over time. There was a 15 percent dropout rate.

Figure 1

*Dropout Over Life of the Study*



**Eligibility.**

Consumers eligible to participate in this study were (1) diagnosed with a psychiatric disability, (2) at least 18 years old (3) not peer facilitators of the MY VOICE program employed at SIDE, and (4) able to read. Participation in the study was voluntary, therefore, those who participated agreed to complete certain research measures as well as use the MY VOICE program to develop recovery goals.

**Recruitment.**

Two information sessions were conducted at SIDE one and two weeks prior to the beginning of the study. At these informational meetings, the study was described as was the MY

VOICE Program. Those interested in participating in the study were scheduled for an initial pre-test interview throughout the following month. The consumers that learned of the study after the information sessions were held through word of mouth or through posters at the implementation site were still able to participate in the study by calling the telephone number or emailing the address provided on the poster. A rolling enrollment method was used where individuals could join the study as they became aware of it. In order to recruit a sufficient number of individuals into the study, and to encourage sufficient follow through completion of the research protocol, an incentive of \$20 was given to each consumer participant at each of three separate occasions: the baseline interview (Time 1), the first post-test interview (Time 2), and the second post-test interview (Time 3) (See Figure 2). Consumers who wished to use the MY VOICE program but did not wish to participate in the study were required to wait until the study period was complete (approximately five months) and then they were able to use the MY VOICE program without participating in the research.

#### **Peer Support Worker Training.**

Four peer support workers employed at SIDE were available to assist consumers in accessing and completing the MY VOICE program. These peer support workers were trained to enter consumers into the program, in how to complete the program, and in how to resolve technical issues that might hinder program completion. The peer support workers were available for assistance the first time consumers accessed the MY VOICE program. After completing the program for the first time, consumers could choose to access the program from a remote internet connection and not utilize the peer support worker from that point forward. A consumer could also return to the CRO for technical assistance every time they accessed the MY VOICE program. Peer support workers were trained to provide technical assistance for completion of



the MY VOICE program and to avoid providing or developing goals for the participant. Peer support workers were trained to ensure that the goals and strengths were consumer driven rather than peer driven.

### **Informed Consent.**

The informed consent process occurred prior to the first interview. Individuals were provided an informed consent form (See Appendix E) which detailed the risks and benefits of participation. Participants were assured that all information gathered would be confidential and that findings would only be reported in aggregate. Participation was voluntary. Consumers who volunteered could discontinue participation at any time without consequence.

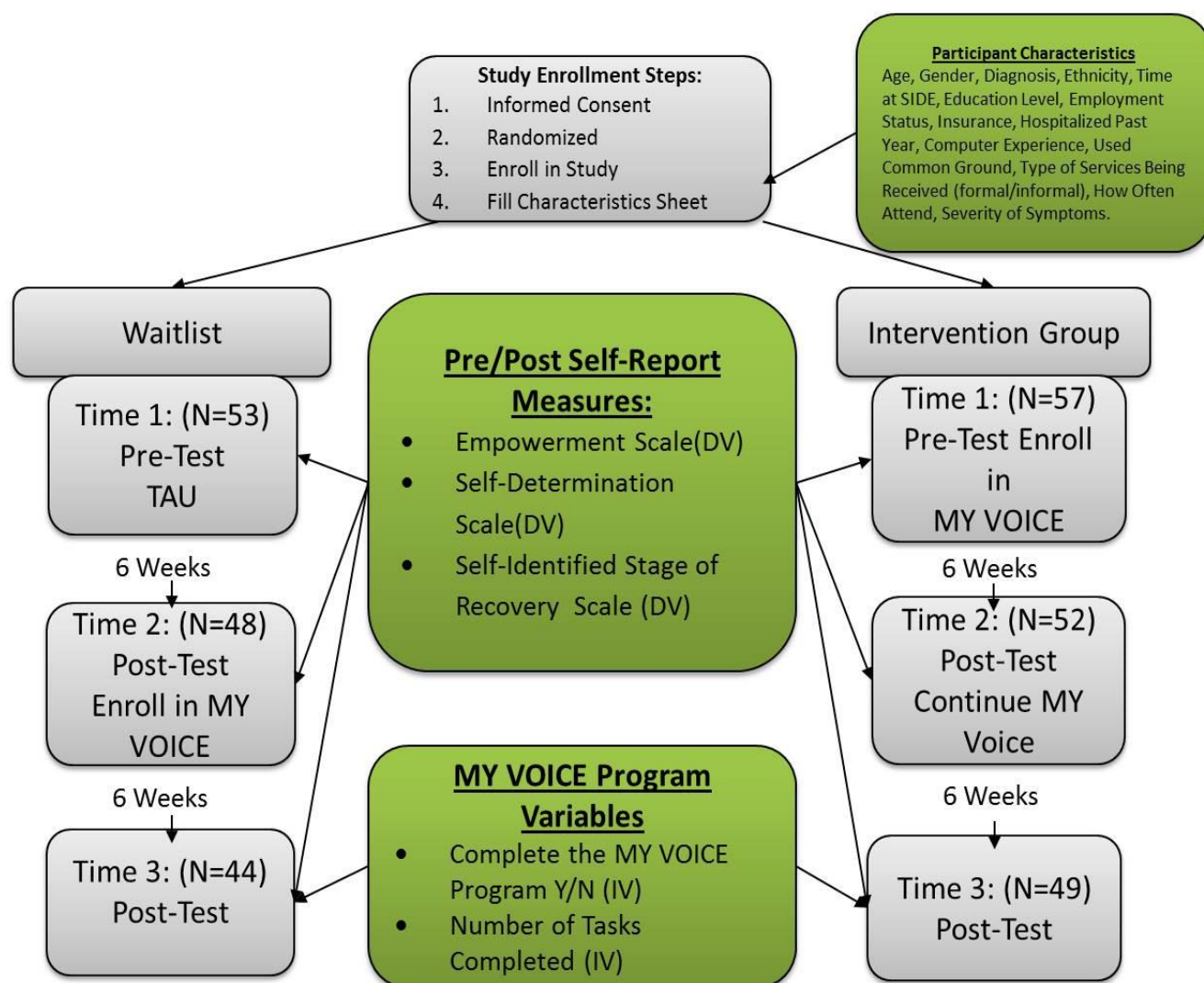
### **Design**

The study was a randomized waitlist controlled group design. Of the 110 who agreed to participate and signed forms indicating their informed consent, 57 were randomly assigned to the intervention group and 53 consumers were randomly assigned to the waitlist group. The waitlist control design was used to allow everyone the chance to use the MYVOICE EDSI while still allowing for comparison. All of the interviews were conducted by the researcher. At the first interview individuals were first asked to provide informed consent and, if consent was provided, they were subsequently randomized into the waitlist or control conditions, and then provided with the Time 1 interview. The Time 1 interview included a questionnaire seeking participant demographic information and three psychometric scales: 1) The Empowerment Scale (Rogers, Ralph, & Salzer, 2010), 2) the Self-Determination Scale (Sheldon, Ryan, & Reis, 1996) and 3) the Self-Identified Stage of Recovery Scale (SIS-R) (Andresen, Caputi, & Oades, 2010). After this initial interview, those in the intervention condition began using the MY VOICE program and those in the waitlist condition continued receiving services as usual. After a six week period,

individuals in both conditions were given a Time 2 follow-up interview. Once an individual on the waitlist condition had completed the Time 2 interview, participants on the waitlist condition began using the MY VOICE program. Individuals in the intervention condition continued using the MY VOICE program after he/she had completed the first posttest. After an additional six week period individuals in both groups were given a Time 3 interview. The Time 2 and Time 3 interviews were simply re-administrations of the Empowerment, Self-Determination, and SIS-R scales. The participant questionnaire and the psychometric scales are described in more detail in the measurement section. Figure 1 illustrates the randomized control waitlist design described.

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Figure 1

*Design for Piloting MY VOICE Self-Directed Recovery Planning***Instrumentation**

Three categories of variables were measured in this pilot study: participant characteristic variables, psychometric self-assessment variables, and MY VOICE program variables. The participant characteristic variables measured included: Age, gender, diagnosis, race/ethnicity, length of time being served at the agency, how often they attend the agency, education level, employment status, type of insurance, whether or not hospitalized in the past year, past computer

experience, whether or not they have used the CommonGround© software program, types of services being received, and self-assessed severity of symptoms. The instrument which assesses each of these participant characteristic self-report variables, which was developed specifically to address the needs of this study, is found in Appendix A.

The MY VOICE program variables include, program completion yes or no, and number of tasks completed. Program completion is operationalized as being able to complete the full MY VOICE process at least once. This means that if a consumer has created at least one task for achieving at least one of their recovery goals they will be considered as having completed the program. Number of tasks completed is operationalized as simply the number of tasks toward completion of a given recovery goal that participants identify as having completed in the MY VOICE program. Program completion and number of tasks completed are assessed by the MY VOICE program and a report can be run which automatically calculates these for each MY VOICE user.

The self-assessment measures include The Empowerment Scale (Rogers, Ralph, & Salzer, 2010), the Self-Determination Scale (Sheldon, Ryan, & Reis, 1996) and the Self-Identified Stage of Recovery Scale (SIS-R) (Andresen, Caputi, & Oades, 2010).

*The Empowerment Scale* (Rogers et al., 2010) is a 25 item instrument designed to measure subjective feelings of empowerment on a 4-point likert scale ranging from ‘strongly agree’ to ‘strongly disagree’ (e.g. “I can pretty much determine what will happen in my life.” 1 strongly agree, 2 agree, 3 disagree, and 4 strongly disagree) (See Appendix B). The Empowerment Scale was validated on a sample of 1,287 individuals receiving services from community mental health centers. The Cronbach’s alpha on the total scale yielded an internal consistency of .82. The empowerment scale has five subscales which are labeled self-efficacy,

perceived power, optimism about and control over the future, and community activism (Rogers, Ralph, & Salzer, 2010). Mean scores on the subscales and for the total empowerment scale can be used as variables in research. In order to capture the participants' overall sense of empowerment, the total empowerment score was used which ranges in score from 1 to 4. Lower scores are equivalent to greater empowerment.

*The Self-Determination Scale* (Sheldon et al., 1996) was designed to assess the extent to which people tend to function in a self-determined way. This scale has good internal consistency with alphas ranging from .85 to .93 across a variety of samples and test-retest reliability of the self-determination scale has been adequate over an eight week period ( $r = .77$ ) (Sheldon & Deci, 1996). The self-determination scale is a short, 10-item scale, with two 5-item subscales. The first subscale is awareness of oneself, and the second is perceived choice in one's actions. The subscales can either be used separately or they can be combined into an overall score. This study used each of these subscales separately because the awareness-of-self subscale assesses elements of emotional awareness which the MY VOICE program was not necessarily created to address. Participants are to indicate which of two statements is more true for them (e.g., "A. I sometimes feel that it's not really me choosing the things I do" and "B. I always feel like I choose the things I do.") (See Appendix C). Participants responded on a 1 to 6 scale where 1 means *only A feels true* and 6 means *only B feels true*. Scores on the subscales and the total score range from 1 to 6.

*The Self-Identified Stage of Recovery Scale* (Andresen et al., 2010). The SISR scale provides two measures of self-identified recovery ranging from stage 1 to stage five (See Appendix D). The five stages are defined as (1) Moratorium (withdrawal, hopelessness and a negative sense of identity), (2) Awareness (hope and an awareness of intact aspects of the self), (3) Preparation (the examination of core values and the implementation of internal and external

resources), (4) Rebuilding (taking steps towards meaningful goals) and (5) Growth (living a fulfilling life and looking towards a positive future). The higher the stage of recovery the further along in the recovery process the individual is. Andresen et al. (2010) found that the SISR has good convergent validity with two other stage of recovery scales namely the Recovery Assessment Scale (RAS) ( $r = .89$ ) (Corrigan et al., 1999) and the Mental Health Recovery Scale ( $r = .80$ ) (MHRM) (Young & Bullock, 2003) and was based on a sample of 281 individuals with psychiatric disabilities participating in community mental health services in Australia. The SIS-R is much shorter than these other two scales and is a consumer self-report measure. The scores on the SIS-R range from 1 to 5.

## **Procedures**

After receipt of approval from the Human Subjects Committee of Lawrence (HSCL), the University of Kansas' Committee on Human Subjects, the procedures for this pilot study began with recruitment of individuals who met study criteria through the previously described informational meetings, word of mouth, and poster announcements. Consumers who were interested in participating called the provided number, used the email address to set up an initial interview, or contacted the researcher in person when he was present at the CRO. At the initial interview, the research project was explained to the consumer. If the consumer chose to participate, she/he was asked to sign the provided informed consent form and then randomized into either the intervention or control group. The statistical program SPSS was used to generate a random number, those assigned an even number were placed in the intervention condition, those assigned an odd number were placed in the waitlist condition. The participant was then given the participant characteristics form (See Appendix A), \$20 in cash, and the Empowerment, Self-Determination, and SIS-R scales (See Appendix B, C, and D) to complete.

All of the individuals (waitlist or control) continued to receive services at SIDE and outside services as usual. Consumers randomized to the intervention group continued receiving services at SIDE and also were provided with a username and password for the MY VOICE program. Using this username and password participants began using the MY VOICE program. The peer support workers present at SIDE were available to answer any questions the participants might have regarding how to complete the program and helped resolve glitches in the electronic system.

In order to ensure that individuals thoroughly knew how to use the MY VOICE program, participants completed MY VOICE for the first time while on site at SIDE. After the MY VOICE process was completed once, the individual enrolled could access the MY VOICE program from any internet connection using their user-name and password, thus participants had the option to revisit and adjust their self-directed recovery plan 24 hours a day, 7 days a week, from an internet connection. Consumers were contacted by the researcher once per month to encourage use of the MY VOICE program and to encourage attendance at the time 2 and time 3 interviews. All participants' enrolled in the MY VOICE program received these reminder phone calls whether they had been accessing the program regularly or not.

After a six week period, participants in the waitlist and intervention groups were given a Time 2 interview. The Time 2 interview included a re-administration of the Empowerment, Self-Determination, and SIS-R scales. During the Time 2 interview, consumers received their second \$20 dollar incentive. After an individual completed the Time 2 interview, if he/she was in the waitlist condition she/he began using the MY VOICE program for the first time. If the individual was in the intervention condition he/she continued using the MY VOICE program for an additional six week period. Once six weeks passed for an individual participant, she/he was

given a Time 3 interview. The Time 3 interview consisted of another re-administration of the Empowerment, Self-Determination, and SIS-R scales. During the Time 3 interview, the consumers received their third and final \$20 dollar incentive, and were asked three open ended questions to conclude the interview. The open ended questions were: 1) What did you like about the MY VOICE program? 2) What did you not like about the MY VOICE program? 3) What would you change to make the MY VOICE program better? These questions were used for evaluative purposes to improve the MY VOICE program and are not formally qualitatively analyzed in the results. However, some of the client statements are used to inform critical reflections in Chapter 5, the discussion section.

### **Analyses**

The four different research questions addressed in this study required different statistical analyses with differing underlying statistical assumptions. The software SPSS 20.0 was used to test underlying assumptions and conduct the various statistical analyses employed in this study.

#### **Question 1: Demographic Predictors.**

The first question, “What participant characteristics predict completion of the MY VOICE program?” was answered using Backward Logistic Regression (See Table 1). Each of the participant characteristics variables (See Appendix A) was included as an independent variable in the logistic regression equation and the dichotomous variable *MY VOICE completion Y/N* was used as the dependent variable. Data from both the intervention and waitlist groups were used in this analysis. The participant demographic variables were used in an exploratory Backward Logistic Regression model that determined which demographic characteristic combinations best predicted completion of the MY VOICE program.



The question “what participant characteristics predict completion of the MY VOICE program?” is an exploratory one without a preconceived notion regarding which variables may be predictors or whether they interact with each other. An exploratory backward Logistic Regression is a viable analysis when 1) the goal of the research question is not explanatory and 2) when causal inferences are made with caution because exploratory regression analysis attempts to find a good set of predictors that account for as much variance as possible without having prior theory (Tabachnic & Fidell, 2011). Logistic Regression in general is an appropriate analysis of prediction of group membership when there is a dichotomous variable such as *completion of MY VOICE yes or no* (Tabachnic & Fidell, 2007). Model fit was analyzed using the -2 Log Likelihood, the chi-square value was analyzed to assess the overall model prediction, and the Wald statistics and p-values were used to determine individual factor statistical significance.

## **Question 2: Differences between Intervention and Control.**

The second research question, “Do consumers who use the program show greater improvement in the outcome variables of self-appraised scores on empowerment, self-determination, and progress in recovery than those in the control group?” was answered through using four separate multivariate linear regression models (See Table 1). Standard multiple regression was used to determine whether the independent variable representing group membership (*group*) predicted changes in empowerment (*empowerT2*) while controlling for education level (*education*) and baseline scores on empowerment (*empowerT1*). Next, standard multiple regression was used to determine whether the independent variable representing group membership (*group*) predicted improvements in perceived choice (*SDPCT2*), a subscale of the self-determination scale, while controlling for education level (*education*) and baseline scores on

perceived choice (*SDPCT1*). Standard multiple regression was used again to determine whether the independent variable representing group membership (*group*) predicted improvements in awareness-of-self (*SDAoS2*), another subscale of the self-determination scale, while controlling for education level (*education*) and baseline scores on awareness of self (*SDAoST1*). Finally, standard multiple regression was used to determine whether the independent variable representing group membership (*group*) predicted improvements in stage of recovery (*SORT2*) while controlling for education level (*education*) and baseline scores on stage of recovery (*SORT1*).

### **Question 3 and 4: Completion of Program and Completion of Tasks.**

The third and fourth questions, “Does completion of the MY VOICE program relate to self-appraisal of empowerment, self-determination, and progress in recovery?” and “Does the number of completed tasks relate to self-appraisal of empowerment, self-determination and progress in recovery?” respectively, were answered by conducting four separate multiple regression models using two blocks of entered variables. In order to answer these questions both groups were combined and the outcome variables were transformed to include only the pre-post assessments on the psychometric scales of empowerment, self-determination, and stage-of-recovery for both groups. Four regressions are used because self-determination was analyzed using its two subscales separately: perceived choice (*SDPC*) and awareness of self (*SDAoS*). In each of the regressions the first block contained the control variables (education level and pretest scores on the outcome of interest) and whether or not the individual had completed the MYVOICE program (*Complete MYVOICE*). The second block added the number of tasks individuals completed (*Complete Tasks*). Multiple Regression analysis allows the researcher to use continuous variables to determine scores on an additional continuous variable (Tabachnic &

Fidell, 2007). Regression is also often used instead of ANOVA/MANOVA to conduct this type of analysis because if the relationships between variables are linear (as opposed to curvilinear) regression will have more power (Seltman, 2012). In addition, regression will provide a chance to detect non-linear relationships and correct for it using data transformations if present while ANOVA/MANOVA does not (Seltman, 2012). See Table 2 for a detailed description of each of the analyses and the variables to be used.

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Table 2

*Matrix of Analyses and Variables*

Research Question	Analysis	Independent Variable(s)	Dependent Variable(s)	Control Variable
1. What participant characteristics predict completion of the MY VOICE program?	Backward Logistic Regression	Age, Gender, Diagnosis, Race/Ethnicity, Time at SIDE, Education Level, Employment Status, Insurance, Hospitalized Past Year, Computer Experience, Used CommonGround®, Type of Services Being Received (formal/informal), How Often Attend.	MY VOICE Completion Y/N	
2. Do consumers who use the program show greater improvement in the outcome variables of self-appraised scores on empowerment, self-determination, and progress in recovery than those in the control group?	Regression	Waitlist or Intervention Group Y/N	Empowerment Scale Self-Determination Scale SIS-R Scale	Education Level  Pretest scores on Empowerment, self-determination and recovery
3. Does completion of the MY VOICE program relate to self-appraisal of empowerment, self-determination, and progress in recovery?	Regression	MY VOICE Completion Y/N	Empowerment Scale Self-Determination Scale SIS-R Scale	Education Level Symptom Level  Pretest scores on Empowerment, self-determination and recovery
4. Does number of completed tasks relate to self-appraisal of empowerment, self-determination and progress in recovery?	Regression	Number of Completed Tasks	Empowerment Scale Self-Determination Scale SIS-R Scale	Education Level Symptom Level  Pretest scores on Empowerment, self-determination and recovery

## Chapter 4: Results

### Demographic Results

Descriptive statistics and frequencies for all variables were conducted and analyzed for outliers and missing data. There were 110 individuals participating at Time 1, 100 individuals participating at Time 2, and 94 individuals participating at Time 3, indicating a corresponding 15 percent dropout rate over the life of the study. Any of the variables which had between 5-15 percent missing cases had the missing values replaced with the mean of the distribution (Mertler & Vanatta, 2010). None of the variables in the analysis had more than 15 percent missing cases. Those with less than 5 percent missing cases did not have missing values replaced (Mertler & Vanatta, 2010).

Chi-square tests of independence, and independent samples *t*-tests were performed to examine the relationships between particular demographic variables and group membership. T-tests of symptom level ( $t(107) = 3.54, p = .41$ ) and age ( $t(107) = 2.2, p = .52$ ) were not significantly related to group membership. In addition, the majority of the demographic variables analyzed using chi squares were also not significantly related to group membership (see Table 1). However, education level ( $X^2(6, N = 110) = 17.87, p < .01, \eta^2 = .26$ ) and computer use ( $X^2(3, N = 109) = 8.64, p < .05, \eta^2 = .28$ ) were significantly related to group membership. Because the variables *education* and *computer use* were related to membership in the treatment group, they were analyzed to determine collinearity using Spearmans rho statistic. These two variables were strongly correlated,  $\rho(108) = .35, p < .001$ . Individuals with higher education levels may also use computers more often (Christensen, 2002). *Education* was chosen as a proxy for both variables and used as a control variable in the analyses.

Baselines scores on the outcome variables were assessed using t-tests. The Awareness-of-self subscale was significantly related to control group membership ( $t(108) = 2.06, p < .052$ ). Table 3 provides frequency distributions chi-square for results for demographic variables, Table 4 provides means, standard deviations, and t-test results for demographic variables, and Table 5 provides means, standard, deviations, and t-test results for initial baseline scores on the outcome variables.

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Table 3

*Chi Square Demographic Comparisons by Group*

Item	Intervention Group n = 57	Control Group n = 53	$\chi^2$
<b>Gender</b>			$\chi^2=3.74$
a) Female	n = 25	n = 33	
b) Male	n = 32	n = 20	
<b>Diagnosis</b>			$\chi^2=1.38$
a) Schizophrenia	n = 26	n = 26	
b) Bipolar	n = 15	n = 17	
c) Major Depression	n = 13	n = 8	
d) Other	n = 3	n = 2	
<b>Race/Ethnicity</b>			$\chi^2=3.95$
a) Native American	n = 2	n = 5	
b) African American	n = 41	n = 34	
c) Caucasian	n = 14	n = 12	
d) Hispanic	n = 0	n = 2	
<b>Length Attending Peer Center</b>			$\chi^2=0.00$
a) 1 yr or less	n = 26	n = 24	
b) Over a year	n = 31	n = 29	
<b>Often Attended Peer Center</b>			$\chi^2=1.75$
a) > once per month	n = 24	n = 29	
b) Once per month or less	n = 33	n = 24	
<b>Education Level</b>			$\chi^2=17.87^{**}$
a) High school or below	n = 22	n = 38	
b) Some college or higher	n = 35	n = 15	
<b>Employment Status</b>			$\chi^2=4.97$
a) Social Security	n = 31	n = 30	
b) Unemployed	n = 19	n = 14	
c) Part-time	n = 7	n = 5	
d) Fulltime	n = 0	n = 4	
<b>Insurance</b>			$\chi^2=0.15$
a) Private	n = 1	n = 1	
b) Medicare/Medicaid	n = 44	n = 40	
c) No Insurance	n = 11	n = 12	
<b>Psychiatric Hospitalization</b>			$\chi^2=1.21$
a) Hospitalized past year	n = 9	n = 13	
b) Not Hospitalized past year	n = 47	n = 40	
<b>Computer Ability</b>			$\chi^2=5.65$
a) Poor	n = 22	n = 28	
b) Good	n = 35	n = 25	

<b>Computer Use</b>			$\chi^2=8.64^*$
a) Never Used	n = 3	n = 12	
b) Used Rarely	n = 15	n = 17	
c) Used Sometimes	n = 15	n = 10	
d) Used Often	n = 23	n = 14	
<b>CommonGround© Use</b>			$\chi^2=0.78$
a) Used	n = 18	n = 13	
b) Never Used	n = 38	n = 40	
<b>Current CMH Services</b>			$\chi^2=0.01$
a) Receive Services	n = 48	n = 45	
b) Don't Receive Services	n = 9	n = 8	

\* $p < .05$ , \*\* $p < .01$

Table 4

*t-test Demographic Comparisons by Group*

Item	Intervention Group	Control Group	<i>T</i>
Age	45.3(9.6)	46.6(11.9)	$t=2.20$
Symptom Severity	5.84(2.1)	6.21(2.6)	$t=3.54$

\* $p < .05$

Table 5

*Baseline Outcome Variables by Group*

	Intervention Group	Control Group	<i>T</i>
Empowerment	2.08(.27)	2.10(.31)	-.518
Awareness of Self	3.66(.98)	3.26(1.05)	2.06*
Perceived Choice	3.48(1.03)	3.17(.99)	1.58
Stage of Recovery	3.07(1.06)	3.08(1.30)	-.018

\* $p < .05$

### Question 1: Demographic Predictors

This section describes the results of Question 1, “What participant characteristics predict completion of the MY VOICE program?” A preliminary multiple regression was conducted to calculate Mahalanobis’ distance to identify outliers and examine multicollinearity among the fifteen demographic predictors. Tolerance for all variables was greater than .1, indicating that multicollinearity assumptions were met. No outliers were identified beyond the chi-square (15,  $N$



= 110) = .001 criterion of 37.697. Therefore no cases needed to be removed prior to Logistic Regression analysis.

Backward logistic regression was conducted to determine if a reduced combination of demographic characteristics might predict completion of the MY VOICE program. After 15 entered steps with non-significant model results, the final backward regression model indicated that the overall model fit of the one remaining predictor (*employment*) was good (-2 Log Likelihood = 77.13), significantly predicted completion of the MY VOICE program ( $X^2(1, N = 110) = 5.89, p < .05$ ), and correctly classified 87% of cases. However, closer inspection of the Wald statistics revealed that, while the overall model was significant, individual employment characteristics did not significantly predict completion (See Table 6). None of the included demographic characteristics predict completion of the MY VOICE program.

Table 6

*Regression Coefficients of Employment Variable\**

	<i>B</i>	<i>Wald</i>	<i>Df</i>	<i>p</i>	<i>Odds Ratio</i>
Disabled		2.54	3	.469	
Unemployed	-.903	2.23	1	.135	.405
Employed Part Time	18.987	.00	1	.999	1.762E+5
Employed Full Time	-1.117	.82	1	.365	.327

\*( $X^2(1, N = 110) = 5.89, p < .05$ )

## **Question 2: Differences between Intervention and Control**

This section describes the results of question 2, “Do consumers who use the MY VOICE program show greater improvement in the outcome variables of self-appraised scores on empowerment, self-determination, and progress in recovery than those in the control group?” Multiple linear regression was used to determine whether each of the outcome variables (empowerment, self-determination, and recovery) were significantly different between the groups. A preliminary multiple regression was conducted to calculate Mahalanobis’ distance to

identify outliers and examine multicollinearity among the variables used in analysis. Tolerance for all variables was greater than .1, indicating that multicollinearity assumptions required for running a logistic regression were met. One outlier was identified well beyond the chi-square (14,  $N = 109$ ) = .001 criterion of 36.123. Therefore this case outlier was removed prior to running the linear regression analyses.

### **Empowerment.**

Standard multiple regression was used to determine whether the independent variable representing group membership predicted level of empowerment while controlling for education level and Time 1 scores on empowerment. Education was controlled for because it was identified as being related to group membership. While regression results revealed that the overall model explained a significant proportion of the variance ( $R^2 = .34$ ,  $F(3, 108) = 17.67$ ,  $p < .001$ ), group membership did not significantly predict empowerment scores at Time 2 ( $b = .029$ ,  $t(108) = .05$ ,  $p = .536$ ) and most of the model predictive capacity came from Time 1 control scores ( $b = .563$ ,  $t(108) = 7.04$ ,  $p < .001$ ). See Table 7 for regression coefficients. There were no statistically significant differences in empowerment identified at Time 2 between the intervention group and the control group.

Table 7

#### *Regression Coefficients Predicting Empowerment at Time 2*

	<i>B</i>	<i>SE(B)</i>	$\beta$
Group	.029	.047	.051
Education	-.005	.018	-.023
Empowerment Time 1	.563	.080	.569*

$R^2 = .34$ ,  $*p < .001$

### **Self Determination.**

Next, standard multiple regression was used to determine whether the independent variable representing group membership predicted level of perceived choice, a subscale of the

self-determination scale, while controlling for education level and Time 1 scores on perceived choice. Regression results revealed that the overall model explained a significant proportion of the variance ( $R^2 = .22$ ,  $F(3, 108) = 10.09$ ,  $p < .001$ ), while group membership individually did not significantly predict perceived choice scores ( $b = -.17$ ,  $t(108) = -1.12$ ,  $p = .267$ ). Baseline control scores were a significant predictor of perceived scores ( $b = .34$ ,  $t(108) = 4.71$ ,  $p < .001$ ). See Table 8 for regression coefficients predicting perceived choice. There were no statistically significant differences detected between the intervention group and the control group on perceived choice at Time 2.

Table 8

*Regression Coefficients Predicting Perceived Choice at Time 2*

	<i>B</i>	<i>SE(B)</i>	$\beta$
Group	-.170	.152	-.100
Education	.088	.058	.135
Perceived Choice Time 1	.342	.073	.410*

$R^2 = .22$ ,  $*p < .001$

Standard multiple linear regression was used again to determine whether the independent variable representing group membership predicted level of awareness-of-self, another subscale of the self-determination scale, while controlling for education level and baseline scores on awareness of self. Regression results revealed that the overall model explained a statistically significant proportion of the variance ( $R^2 = .16$ ,  $F(3, 108) = 6.57$ ,  $p < .001$ ), while group membership individually did not significantly predict awareness-of-self scores ( $b = .077$ ,  $t(108) = .434$ ,  $p = .67$ ), and most of the model predictive capacity came yet again from baseline control scores ( $b = .357$ ,  $t(108) = 4.23$ ,  $p < .001$ ). See Table 9 for regression coefficients predicting awareness-of-self. There were no statistically significant differences in awareness-of-self between the intervention group and the control group at Time 2.

Table 9

*Regression Coefficients Predicting Awareness of Self at Time 2*

	<i>B</i>	<i>SE(B)</i>	$\beta$
Group	.077	.179	.041
Education	.074	.068	.100
Awareness of Self Time 1	.357	.084	.386*

$R^2 = .16$ ,  $*p < .001$

**Recovery.**

Multiple linear regression was used to determine whether the independent variable representing group membership predicted level of stage of recovery while controlling for education level (*education*) and Time 1 scores on stage of recovery. In this instance regression results revealed that the overall model explained a significant proportion of the variance ( $R^2 = .27$ ,  $F(3, 108) = 13.2$ ,  $p < .001$ ) and that group membership significantly predicted stage of recovery scores ( $b = -.61$ ,  $t(108) = -3.33$ ,  $p = .001$ ) even while controlling for the baseline control scores ( $b = .347$ ,  $t(108) = 4.5$ ,  $p < .001$ ). The effect size for the analysis ( $d = .66$ ) was found to meet Cohen's (1988) convention for a medium effect size ( $d = .50$ ). See Table 8 for regression coefficients predicting stage of recovery. Statistically significant differences were detected in stage of recovery between the intervention group and the control group. The intervention group had higher stage of recovery scores at Time 2 than did the control group.

Table 10

*Regression Coefficients Predicting Stage of Recovery at Time 2*

	<i>B</i>	<i>SE(B)</i>	$\beta$
Group	-.610	.183	-.287*
Education	.093	.072	.113
Stage of Recovery Time 1	.347	.077	.382*

$R^2 = .27$ ,  $*p \leq .001$

### **Questions 3 and 4: Completion of Program and Completion of Tasks**

This section describes the results from Question three and Question four: “Does completion of the MY VOICE program or number of tasks completed relate to self-appraisal of empowerment, self-determination, and progress in recovery?” Completion of MY VOICE means that the individual has answered all of the questions in the program and has developed some recovery goals with corresponding tasks. Completion of tasks means that the individual re-entered the MY VOICE program for at least a second time and identified that they have completed some of the tasks they had developed previously. In order to answer these questions both groups were combined and the outcome variables were transformed to include only the pre-post assessments on the psychometric scales of empowerment, self-determination, and stage-of-recovery for both groups. Each of the outcome variables, empowerment, self-determination and stage of recovery, were analyzed by running four separate regression models using two blocks of entered variables. Four regressions are used because self-determination was analyzed using its two subscales separately: perceived choice and awareness-of-self. In each of the regressions the first block contained the control variables (education level, symptom level, and pretest scores on the outcome of interest) and whether or not the individual had completed the MY VOICE program. The second block added the number of tasks individuals completed to the prediction model.

However, prior to running these analyses, a preliminary multiple regression was conducted to calculate Mahalanobis’ distance to identify outliers and examine multicollinearity among the 10 variables used in the analyses for questions 3 and 4. Tolerance for all variables was greater than .1, indicating that multicollinearity assumptions were met. No outliers were

identified beyond the chi-square (10,  $N = 108$ ) = .001 criterion of 29.588 and no additional cases were removed.

### **Empowerment.**

A multiple regression analysis was conducted to determine whether completion of the MY VOICE program predicted empowerment scores. The results of this analysis showed an overall significant model of prediction ( $R^2 = .46$ ,  $F(3, 108) = 22.26$ ,  $p < .001$ ) but that completion of the MY VOICE program did not significantly predict empowerment scores ( $b = -.004$ ,  $t(108) = .07$ ,  $p = .94$ ) rather that symptom level ( $b = -.016$ ,  $t(108) = -.153$ ,  $p > .05$ ) baseline empowerment scores were the primary predictive variable ( $b = .528$ ,  $t(108) = 7.86$ ,  $p > .001$ ). The overall model continued to be significant for block 2 ( $R^2 = .46$ ,  $F(3, 108) = 17.64$ ,  $p < .001$ ), however, the added variable *complete tasks* did not significantly predict empowerment scores. The regression coefficients for the final model are included in Table 9. Completing MY VOICE or completing tasks were not statistically significant predictors of empowerment.

Table 9

*Regression Coefficients Predicting Empowerment for Entire Sample Post Intervention*

	<b>Block 1</b>			<b>Block 2</b>		
	<i>B</i>	<i>SE(B)</i>	$\beta$	<i>B</i>	<i>SE(B)</i>	$\beta$
Education	-0.05	0.037	-0.099	-0.049	0.037	-0.098
Symptom Level	-0.016	0.008	-.153*	-0.016	0.008	-.153*
Complete MY VOICE	0.004	0.055	0.005	0.005	0.056	0.006
Empowerment Prior Intervention	0.528	0.067	-.606**	0.527	0.068	.606**
Complete Tasks				-0.003	0.027	-0.008

\* $p < .05$ , \*\*  $p < .001$

### **Self Determination.**

Next two multiple regression analyses were conducted to determine whether completion of the MYVOICE program predicted self-determination scores. These two regressions were run separately for each subscale of self-determination: 1) perceived choice and 2) awareness of self.

The results of the perceived choice analysis showed an overall significant model of prediction ( $R^2 = .43$ ,  $F(3, 108) = 5.87$ ,  $p < .001$ ) but that completion of the MYVOICE program did not significantly predict perceived choice scores ( $b = .287$ ,  $t(108) = 1.23$ ,  $p = .22$ ) rather that symptom level ( $b = .013$ ,  $t(108) = .035$ ,  $p = .05$ ) and baseline perceived choice scores were the primary predictive variables ( $b = .32$ ,  $t(108) = 3.85$ ,  $p < .001$ ). An additional block was added to the analysis to determine if number of completed tasks predicted improvements in perceived choice. The overall model continued to be significant ( $R^2 = .43$ ,  $F(3, 108) = 4.71$ ,  $p < .001$ ), however, the added variable did not significantly predict perceived choice scores ( $b = .058$ ,  $t(108) = .495$ ,  $p = .62$ ). The regression coefficients for the final model are included in Table 10.

A multiple regression analysis was also conducted to determine whether completion of the MYVOICE program predicted awareness-of-self scores. The results of this analysis showed an overall significant model of predication ( $R^2 = .21$ ,  $F(3, 108) = 7.02$ ,  $p < .001$ ) but completion of the MYVOICE program did not significantly predict awareness-of-self scores ( $b = -.187$ ,  $t(108) = -.673$ ,  $p = .502$ ) rather, the baseline awareness-of-self scores were the primary predictive variable ( $b = .529$ ,  $t(108) = 5.13$ ,  $p < .001$ ). A second block was used in the analysis to determine if number of completed tasks predicted improvements in awareness-of-self. When the second block was conducted the overall model continued to be significant ( $R^2 = .21$ ,  $F(3, 108) = 5.57$ ,  $p < .001$ ) however, the added variable *complete tasks* did not significantly predict awareness-of-self scores ( $b = -.018$ ,  $t(108) = -.132$ ,  $p < .895$ ). The regression coefficients for the final model are included in Table 11. The regression analyses of both the self-determination subscales (perceived choice, and awareness of self) reveal no significant changes in self-determination from completion of the MYVOICE program or completed tasks.

Table 10

*Regression Coefficients Predicting Perceived-Choice for Entire Sample Post Intervention*

	Block 1			Block 2		
	<i>B</i>	<i>SE(B)</i>	$\beta$	<i>B</i>	<i>SE(B)</i>	$\beta$
Education	0.312	0.157	0.178	0.303	0.159	0.173
Symptom Level	0.013	0.034	.035*	0.012	0.035	0.033
Complete MY VOICE	0.287	0.234	0.111	0.270	0.237	0.104
Empowerment Prior Intervention	0.324	0.084	.355**	0.330	0.085	.362**
Complete Tasks				0.058	0.117	0.045

\* $p = .05$ , \*\*  $p < .001$

Table 11

*Regression Coefficients Predicting Awareness-of-Self for Entire Sample Post Intervention*

	Block 1			Block 2		
	<i>B</i>	<i>SE(B)</i>	$\beta$	<i>B</i>	<i>SE(B)</i>	$\beta$
Education	0.177	0.185	0.084	0.180	0.187	0.086
Symptom Level	-0.035	0.039	-0.078	-0.035	0.040	-0.078
Complete MY VOICE	-0.187	0.277	-0.06	-0.181	0.281	-0.058
Empowerment Prior Intervention	0.53	0.102	.461**	0.529	0.103	.460**
Complete Tasks				-0.018	0.137	-0.012

\* $p < .05$ , \*\*  $p < .001$

**Recovery.**

Finally, a multiple regression analysis was conducted to determine whether completion of the MYVOICE program predicted stage of recovery scores post intervention. The results of this analysis showed an overall significant model of predication ( $R^2 = .18$ ,  $F(3, 108) = 5.87$ ,  $p = .001$ ) but completion of the MYVOICE program did not significantly predict stage of recovery scores ( $b = -.29$ ,  $t(108) = -1.10$ ,  $p = .22$ ). Instead it was found that symptom level ( $b = .078$ ,  $t(108) = 2.26$ ,  $p < .05$ ) and baseline recovery scores were the primary predictive variables ( $b = .24$ ,  $t(108) = 3.30$ ,  $p = .001$ ). An additional block was added to the analysis to determine if number of completed tasks predicted improvements in stage of recovery scores. When tasks completed was added to the regression, the overall model continued to be significant ( $R^2 = .21$ ,  $F(3, 108) =$



5.47,  $p = .001$ ). However, completed tasks did not predict increases in stage of recovery ( $b = -.212$ ,  $t(108) = -1.83$ ,  $p = .07$ ). The regression coefficients for the final model are included in table 12. When analyzing the combined sample it appears that neither completion of the MY VOICE program or completing additional task lead to changes in empowerment, self-determination, and stage of recovery.

Table 12

*Regression Coefficients Predicting Stage of Recovery for Entire Sample Post Intervention*

	<b>Block 1</b>			<b>Block 2</b>		
	<i>B</i>	<i>SE(B)</i>	$\beta$	<i>B</i>	<i>SE(B)</i>	$\beta$
Education	0.247	0.158	0.14	0.278	0.158	0.158
Symptom Level	0.078	0.034	.207*	0.078	0.034	.206*
Complete MY VOICE	-0.287	0.235	0.11	-0.235	0.234	-0.09
Empowerment Prior Intervention	0.238	0.072	.301**	0.253	0.072	.319**
Complete Tasks				-0.212	0.116	-0.165

\* $p < .05$ , \*\*  $p < .001$

## Chapter 5: Discussion

Individuals with psychiatric disabilities have consistently advocated for increased self-direction and decision-making responsibilities in their treatment (Klein et al., 2007; Noble, 2004) and there is some evidence to suggest that increasing consumer choice and control can lead to greater engagement in care and treatment outcomes (Swift & Callahan, 2009). Electronic decision support interventions (EDSI's) have been developed to help increase consumer self-determination and decision-making in care (Drake, Deegan, & Rapp, 2010). The present study is important because while empowerment, self-determination, and recovery are included in the rationale for consumer participation in EDSI's, no known studies have directly explored whether participation in an EDSI will actually lead to consumer identified increases in empowerment, self-determination, and recovery; nor do known EDSI's currently available to consumers explicitly include a focus on consumer strengths.

While conceptualized as a SDC program, MY VOICE incorporates elements from both SDC and SDM. From SDC, MY VOICE borrows the concepts of informed self-assessment and determining how and by whom consumer needs should be met. From SDM, MY VOICE borrows a focus on helping people make decisions and clarify values, the development of technological decision aids which help individuals increase their voice in treatment and helps individuals make informed decisions. The present study of the MY VOICE EDSI seized the opportunity to expand the breadth of inquiry in SDC-SDM research.

Consumer focused EDSI's are meant to help consumers clarify their values, identify treatment preferences, and help them advocate for themselves during shared-decisions with providers. Thus, EDSIs may empower consumers in their treatment decisions and in promoting self-direction and recovery. It was anticipated that the MY VOICE program would facilitate

self-determination, empowerment and progress in recovery by providing a means for individuals to conduct meaningful self-directed self-assessments of their strengths, identify their personal recovery goals, link their strengths to their goals, and identify initial tasks toward goal completion. The purpose of this pilot study was to determine what characteristics predicted completion of the MY VOICE EDSI program and to test the theory that participation in the self-directed MY VOICE program may lead to increases in consumer self-identified empowerment, self-determination and recovery. Specifically, this study tests the relationship between participation in MY VOICE: Strengths-based and Self-Directed Recovery program with scores on The Empowerment Scale (Rogers, Ralph, & Salzer, 2010), the Self-Determination Scale (Sheldon, Ryan, & Reis, 1996) and the Self-Identified Stage of Recovery Scale (SIS-R) (Andresen, Caputi, & Oades, 2010), while controlling for baseline scores on these measures. This study used a randomized controlled waitlist design to answer the following research questions:

- (1) What participant characteristics predict completion of the MY VOICE program?
- (2) Do consumers who use the MY VOICE program have higher posttest scores on the outcome variables of self-appraised empowerment, self-determination, and progress in recovery than those in the control group?
- (3) For those who complete the MY VOICE program, are there higher posttest scores on the outcome variables of self-appraised empowerment, self-determination, and progress in recovery?

(4) Do the number of completed tasks in the MY VOICE program relate to higher posttest scores on the outcome variables of self-appraised empowerment, self-determination and progress in recovery?

It was found that 1) none of the demographic characteristics measured predicted completion of the MY VOICE program, 2) individuals who participated in the MY VOICE program had higher scores on self-appraised progress in recovery when compared to controls ( $p < .001$ ), while no changes were noted between groups on empowerment or self-determination scores, 3) completion of the MY VOICE program was not a statistically significant predictor of empowerment, self-determination or recovery, and 4) the number of tasks an individual completed post completion was not a statistically significant predictor of empowerment, self-determination, or recovery. In this Chapter, these findings are reviewed and ideas for future research are presented.

One of the primary values driving research on consumer focused EDSI interventions is the belief that consumer voice is important. For evaluative purposes, at the conclusion of the Time 3 interview consumers were asked to indicate what they liked about the program, what they didn't like about the program, and how they would change the program to make it better. While the questions asked in the present study were best answered through quantitative analyses, responses to these evaluative questions provide clues for understanding some of the quantitative findings and so are inserted where appropriate in this discussion chapter. The consumer statements are helpful for envisioning the future of the MY VOICE program by acknowledging what is important to consumers and then setting about devising ways to learn more through future rigorous research design. This chapter will discuss the results of this study in relation to

1) the limitations and strengths 2) the salient findings 3) the relevance to social work, and 4) implications for practice, policy, and research.

### **Limitations and Strengths**

The MY VOICE computer program was implemented at Socialization, Interdependence, Development, and Empowerment (SIDE), an independent non-profit, multi-service, consumer run organization (CRO) located in an urban area of Kansas City, KS. As a consumer run organization there are less formal mechanisms for entering services and formal diagnostic criteria. Formalized case notes, and treatment plans are not always required at these centers. Therefore, much of the formalized data which could have augmented a study was not available for analysis at the CRO. The present study relied solely on the self-report of the individuals participating, and, for example, some individuals may have identified a different primary diagnosis than what would have been reported in their formal case files.

Most participants were African American, were receiving disability payments, and were receiving services from the local community mental health center, therefore the results are not generalizable to populations beyond this particular urban region. In addition, while participants identified whether they were receiving services at a community mental health center, they were not asked to identify what types of services they were receiving, such as whether they were receiving outpatient services, case-management, therapy/counseling, or medication management. This means that the populations studied here could represent a wide range of individuals who might seek services at a mental health center. For instance, there is no differentiation made in the sample between individuals who receive very few services and those who receive very intensive services at the community mental health center.

While randomization to group assignment occurred prior to the time 1 data interviews the researcher was also not blind to which participants were in the intervention and control groups. The researcher also had many roles in the study, as recruiter, data collection, interviewer, and even peer support worker when one wasn't available to assist a participant. It is possible that these multiple roles may have introduced interviewer bias.

The MY VOICE program relies on peer support workers to help individuals navigate the program and assist users of the program when they get stuck. Use of the peer support workers added a dynamic to the MY VOICE program that was not controlled for in the present study. For instance, peer support workers are employed at the CRO during their regularly scheduled times. The regularity of their visits means that some participants who only attend the CRO to use the MY VOICE program during certain times may have had greater exposure to one peer support worker as opposed to equal exposure to all peer support workers. Ways in which this may have influenced the results are further articulated in the following sections.

While there are certainly limitations with this study, there are strengths as well. This pilot study of MY VOICE tests an EDSI program which was designed to build on previous research already conducted on EDSI's. In addition, the study used a waitlist controlled randomized trial design which includes many elements which increase rigor and confidence in the results. Participants were randomized to avoid sampling bias, there was a control group to compare the intervention group with, and there was a time series.

Ethically, when using interventions that have the potential to help clients it is important to not deny participants these potentially beneficial interventions simply for the purpose of forming a control group. The waitlist design allowed all participants to use the MY VOICE program so that no individuals were denied the service. Those who participated in the study

were individuals with psychiatric disabilities whose voice is often downplayed in treatment and whose participation in research is often limited to their clinical record. In addition, doing research with a primarily African American, low socio-economic status, urban population is important as often mental health interventions are developed from studying high socio-economic Caucasians. The intervention being studied places importance on client voice and attempts to determine how effective the intervention is at increasing empowerment, self-determination, and recovery. While the limitations of the study provide some caution, the rigor of using a randomized waitlist controlled design is a strength that supports the initial findings from this study.

### **Discussion of Salient Findings**

When discussing the results of this study it is important to recognize that there are many possible explanations. The explanations described here are grounded in the statistical results, augmented by client self-report, and are also generated from personal experience of the researcher. Each question which this study attempts to answer is reviewed and potential interpretations of the results found follow.

#### **Demographic Predictors of Completion for Both Groups.**

Results of the backward logistic regression indicate there were no statistically significant demographic variables that predicted MY VOICE completion. This was not a comparison between intervention and control groups, but rather an analysis of the combined group once everyone who was participating had started using the program. The fact that peer support workers were present to help participants continue through the program if they ran into trouble may have influenced these findings. For instance, if a participant was confused by a certain section of the MY VOICE program, the peer support worker could help explain or assist, and

then help the participant navigate the rest of the program. If participants asked peer workers to do so, the peer support workers would type the participants' responses for them. Having someone present to help navigate difficulties in program use may have obscured demographic predictors of MY VOICE completion that may have otherwise been evident. This is consistent with Adams (2007) survey of 82 outpatient consumers and 30 self-help mental health consumers regarding their opinions of EDSI's. Perceived ease of use was the primary indicator of whether or not consumers preferred to use an ESDI, although this was not related to actual computer skill ability. If the primary indicator of using an ESDI is ease of use then it may be that having a peer support person present to make the program easier to use increases completion rates across demographic characteristics. Participant statements seem to support this explanation, for example one individual stated "computers really scare me...I liked best that I had a helper to help me type and use the computer." Another stated, "...the peer support made it comfortable to ask questions and helped me type when I got stuck."

Alternatively, it may be that the demographic characteristics measured here are simply not good variables for predicting completion of an ESDI. For instance, while completion rates and demographic predictors were not measured in previous studies, there are some studies which suggest that the majority of consumers are capable of using EDSI's generally (Adams, 2006; Deegan, 2007, Woltman et al., 2010). Several participant statements also support this explanation. While many client statements indicate that portions of the MY VOICE program were difficult, many also note that the computer was easier to use than they expected. For instance, "I got to remember some of the things I learned in the computer class. I guess I'm not such a computer dumb dumb" and "It was easier to use than I thought it was going to be."



### **Differences between Intervention and Control Groups at Time 2.**

It was hypothesized that those who use the MY VOICE program would show greater increases in self-reported empowerment, self-determination, and recovery than those in the control group. The only statistically significant result was that those in the intervention group had higher scores on recovery at Time 2 than those in the control group ( $p < .001$ ); changes in empowerment and self-determination scores were not statistically significant. Participation in the MY VOICE strengths-based and self-directed recovery EDSI may lead to increases in recovery for participants. However, further research is needed to determine if any increases in recovery are due to EDSI participation alone, or to additional influences such as the relationship with the peer support worker or the combination of MY VOICE participation and peer support relationship. The quality of the peer support relationship was not captured in the present study and future studies should consider taking the relationship between the worker and participant into account.

In addition, Shared-Decision Making contains several components which MY VOICE incorporates. The first is a focus on facilitating a decision making process. The MY VOICE program helps participants make decisions about the values and goals that are important to them. Similar to SDM where a good decision is defined as one that is based on client values and preferences (O'Connor et al., 2002) the MY VOICE program helps consumers identify the values they hold dear and link them with what they decide their ultimate recovery goals are. Participants are then making more informed decisions about their care which is a component of shared-decision making. The present study lends support to the idea that facilitating a decision making process that helps individuals articulate their own values and goals through use of an EDSI may lead to changes in stage of recovery.

It is interesting to consider possible reasons why the outcome variables of self-reported empowerment and self-determination were not statistically significant between groups. It may be that there is a dosage effect for empowerment self-determination. It may take more time with an EDSI intervention to show changes in empowerment and self-determination while changes in stage of recovery can be more fluid. For instance, the self-determination scale is meant to capture the relatively stable human characteristic of self-determination (Sheldon et al., 1996), while the stages of recovery scale is meant to capture nuanced changes in recovery (Andresen et al., 2003; 2006). The participants used MY VOICE for approximately six weeks and accessed the program only three times on average. It may be that individuals need to participate in the MY VOICE program for a much longer dosage period before changes in self-determination and empowerment become apparent, while stage of recovery is more sensitive to small changes and dosages. Of course, participation in the MY VOICE program may not produce increases in empowerment or self-determination at all, despite dosage.

The instruments used may have been challenging for this population of mental health consumers. For example, some participants found filling out the self-determination questionnaire more confusing and difficult than they did the completion of the empowerment and stage of recovery questionnaires. Of the three psychometric scales used in this study, the self-determination scale was the only one not validated with a sample of individuals with severe psychiatric disabilities. It may be that the self-determination scale needs to be validated with this population and perhaps adjusted to be less confusing for individuals with severe psychiatric disabilities. In the present study, the confusion and difficulty with the instrument may have influenced the results. In addition, the self-determination scale contains elements that the MY VOICE program was not designed to address. For instance the self-determination scale contains

elements of emotional awareness-of-self which the program is not programmed to identify. It may be that it takes longer for these elements to be influenced by MY VOICE program participation.

The statistically significant finding that those in the intervention group had higher scores on recovery at Time 2 than those in the control group ( $p < .001$ ) provides some initial evidence that participation in the MY VOICE strengths-based and self-directed recovery EDSI may lead to increases in recovery for participants. While the study was unable to detect what caused this improvement in stage of recovery, it does lend compelling support for the contention that some element(s) of participation in the MY VOICE program, as it is presently constituted, may lead to changes in stage of recovery.

#### **Completion of Program and Completion of Tasks.**

The MY VOICE program was hypothesized to predict increases in self-reported empowerment, self-determination and progress in recovery, and that because the consumer self-identifies the tasks to be accomplished, the number of tasks completed would predict increases in self-reported empowerment, self-determination, and progress in recovery. Results indicate that completion of the MY VOICE program and the number of tasks completed were not statistically significant predictors of improvement on self-reported empowerment, self-determination, or recovery. There are many possible reasons why these findings might not be significant, including 1) MY VOICE input inaccuracies 2) The quality of the use of MY VOICE, and 3) the influence of other variables not captured in the present study.

#### ***Input inaccuracies.***

The MY VOICE program is completely self-directed. This creates inherent issues with accuracy. For instance, a person may have indicated that they completed tasks in the MY

VOICE program when in reality they had not. They may just have wanted to do a different task even though the current task was not completed and they simply indicated the task was completed in order to add a new task. They may also have indicated that they completed a task because they did not want to do it anymore and did not know how to remove a task by indicating that it was not complete in the program. Many participants reported that this portion of the MY VOICE program was confusing. For example, one person stated “Updating your plan was hard, make it easier to update goals and tasks...make it clearer how to do that.” Individuals may have also indicated that they had completed tasks in order to please the peer support worker or researcher. In addition, individuals may have completed many tasks and never indicated that they had made this progress in the computer. One client disclosed that he carried the MY VOICE printout of his goals and tasks wherever he went. When he completed a task he simply indicated so by checking it off his paper printout but never entered this information into the MY VOICE program itself. These types of reporting inaccuracies may make completion of MY VOICE tasks a poor measure for predicting improvement in recovery, empowerment, or self-determination. It may also be that completion of tasks, even with accurate input, does not capture the reasons why there were increases in recovery between the treatment group and control group.

### *Quality of use.*

It is possible, in fact likely, that different people used the MY VOICE program in different ways. For instance, one person may have rushed through the program. Another person may have taken more time, identified more meaningful strengths and tasks, and created a more meaningful recovery plan. Therefore, simple completion of the MY VOICE program may not be a good measure of why someone is experiencing improvement in recovery stage. In other words, there may be a difference between low quality completion and high quality completion. High

quality completion might be characterized by someone taking the MY VOICE process seriously and spending time making meaningful goals and tasks. Low quality completion might mean the individual rushes through MY VOICE without spending much thought, time or energy with the end goal of just getting the program completed. Perhaps there is something about articulating one's goals and tasks in a high quality manner that is leading to the improvement in recovery at Time 2 that isn't quantifiable at this point. For instance, it may not be a simple matter of articulating a goal, it may be the quality of the goal articulated, the quality of the strengths identified, or the quality of the task completed, rather than the quantity of these measures that is producing the result.

***Other variables.***

Even with accurate input and high quality, completion and tasks completed may still not be good predictors of empowerment, self-determination, or recovery. While there is some evidence that participation in the MY VOICE program may help increase stage of recovery for those who participate in comparison to those in the control group at Time 2, initial analyses seem to indicate that completion of tasks and completion of the MY VOICE program are not the important predictors of this improvement. It may be that there are other uncontrolled-for variables present through participation in MY VOICE that are important predictors other than completion of MY VOICE or number of tasks completed. For instance, it may be that because the MY VOICE program was located within a peer support center and participants' started visiting with peers or a peer support worker more often because of using the program, their stage of recovery increased. There were many people who did not attend SIDE often but started to attend SIDE more often after initiating the MY VOICE program. Some of these people may have started visiting the peer workers and other participants/peers and built a sense of

community they did not have prior to starting the MY VOICE Program. For instance one participant stated “I liked learning how to work the computer, I've never done that before...and then I liked saying hi to other people who were using the computer.” It may also be that those who participated in the MY VOICE program formed a therapeutic relationship with the peer support workers which influenced participants' recovery outside of MY VOICE participation.

Participants provided this feedback:

“I liked making my recovery goals and I liked [the peer support worker], his rapport is good!”

“I liked the one to one thing. I liked sitting down with the peer support worker to talk...”

“The peer support workers were genuine and cared.”

“It was not dehumanizing, it was empowering. It was very educational and [the peer support worker] is cool. I like that there is one on one while we fill it out. If we have questions [the peer support worker] answers us and don't make us feel stupid. [The peer support workers] are nice. It was really nice.”

Further, some combination of MY VOICE participation, relationship with the peer support worker, and community at the peer support center may have contributed to the improvement found in recovery.

Previous research indicates that the therapeutic relationship and working alliance may influence outcomes (Horvath & Symonds, 1991; Lambert & Barley, 2001). Therefore, it is possible that the MY VOICE EDSI itself is a moderator or mediator of a therapeutic relationship with the peer support worker which facilitates increases in recovery.

Finally, the non-linearity of recovery must be considered. Completion of the program yes / no and the number of tasks an individual completes are linear variables while recovery is conceptualized as a dynamic and often cyclical process (Starnino, 2009). It is possible that MY VOICE completion yes or no, and tasks completed are not good at predicting recovery and that

different variables with greater variance which capture this dynamic process might be more useful as predictors.

### **Relevance to Social Work**

Social work is distinctly concerned with social justice and empowering marginalized populations. Individuals with psychiatric disabilities are a population which has traditionally been served by social workers in part because of their marginalized status and the lack of power they wield in society and in treatment (Strickler, 2009). Social workers should continue to be engaged in researching interventions which attempt to help balance the power differential these individuals experience. Social workers provide the majority of mental health treatment in America (SAMHSA, 2001) and need to stay abreast of developing movements, such as the use of EDSIs to enhance consumer power. Electronic decision support interventions have been developed to help consumers increase consumer self-determination and decision-making in care (Drake, Deegan, & Rapp, 2010). As more EDSI's are developed and become available there is the potential for some EDSI's to be less beneficial than others. Social work research on EDSI's should focus on knowing more about what is likely to benefit consumers and maximize empowerment and self-determination.

The present study is relevant to social work because while empowerment, self-determination, and recovery are included in the rationale for consumer participation in EDSI's, no known previous studies have directly explored whether participation in an EDSI will actually lead to consumer identified increases in empowerment, self-determination, and recovery; nor do known EDSI's currently available to consumers explicitly include a focus on consumer strengths. Further research on EDSI's should continue to make explicit what types of EDSI's are more effective at assisting individuals with psychiatric disabilities. Future research should also

identify which elements within EDSI programs actually predict changes in empowerment, self-determination and recovery.

Focusing on strengths is an important aspect of social work practice (NASW, 2006) and mental health care and social work are increasingly using electronic forms of communication, case management, and mental health treatment. As treatment continues to shift toward the use of online and electronic components it is important to social workers to study and advance electronic interventions which are consistent with a strengths focus as opposed to electronics interventions where a strengths focus is lacking.

In addition to its focus on strengths the MY VOICE EDSI merges elements from both the Self-Directed Care and Shared-Decision Making models. From SDC, the MY VOICE program borrows the concepts of informed self-directed assessment and determining how and by whom consumer needs should be met. From SDM, MY VOICE borrows a focus on technological decision aids which help individuals increase their voice in treatment and make informed decisions. The SDM and SDC models have political and consumer backing (SAMHSA, 2004) and therefore are likely to become more commonly available. Researchers and educators need to determine what the place of social work is in this new health care decision making and delivery paradigm.

Social work has distinguished itself from other helping professions through its focus on facilitating change (Fraser, 2004) and research in the social work field entails the study of interventions and the development of systematic change strategies (Fraser, 2004; Thyer, 2007) at the micro, mezzo, and macro levels. Similarly, some have argued that social work endeavors to improve the *goodness-of-fit* between the person and the environment (e.g. De Hoyos & Jensen, 1985). While also being consistent with many of the principles and values of social work, both



SDC and SDM are interventions that are geared toward systems change at multiple levels (e.g. Drake, Deegan, & Rapp, 2010). Both could arguably be considered interventions in that they assist individuals in navigating their environments with the aim of increasing recovery, empowerment, and goodness-of-fit within the community. With social workers providing the majority of mental health treatment in America (SAMHSA, 2001) and SDC and SDM interventions having the ability to transform mental health services into more collaborative and empowering systems, the development of new methods to tap consumer power is critical. The MY VOICE program is built on elements of from both SDC and SDM, is an electronic decision support intervention, contains an explicit strengths focus, and is designed to help a traditionally marginalized population increase their recovery and their voice in treatment. While the research presented here does not unequivocally confirm its ability to do so, further inquiry following well-designed protocols is appropriate.

### **Implications**

As an appropriate topic for social work investigation, the results of this study can be used to draw implications for practice, policy and research.

#### **Practice.**

The MY VOICE EDSI was implemented at a peer run organization facilitated by peer support workers, all of whom are diagnosed with a psychiatric disability themselves. While peer support workers provide valuable mental health services (Mead & MacNeil, 2006), peer support workers continue to struggle with identifying their unique roles in mental health treatment (Chinman, 2000). Peer support workers who were facilitators of the MY VOICE program reported that they appreciated the structure that the MY VOICE program provided and that it could be used to focus their supportive efforts in facilitating recovery for the consumers

with whom they are working. This is consistent with previous reports from peer support workers who have facilitated other EDSI interventions (Deegan, 2007) and is particularly relevant given the finding that participation in the MY VOICE EDSI may help consumers advance their stage of recovery. Consumer run organizations may want to consider implementing an EDSI to provide for structured conversations about recovery with consumers and for the development of recovery goals and tasks. In other words, it is possible that implementing an EDSI may not only help consumers make progress in their recovery but may also provide a clear role for the peer support worker.

Community mental health centers may also want to consider implementation of an EDSI to help create clear roles for peer workers and to help facilitate recovery for consumers. For instance, there has been recent concern that some peer support workers are being relegated to menial positions by community mental health centers rather than being utilized in appropriate and meaningful ways (Gates & Akabas, 2007). Being relegated to menial positions has sometimes been the result of a lack of clear peer support worker role and job description (Gates, 2010). Employing peer workers as facilitators of an EDSI meant to assist in consumer recovery may provide a meaningful and clear role.

Consumers who use the MY VOICE program actually develop their own recovery plans and can implement the plans themselves. Some of the goals and tasks they develop may fall within the range of traditional community mental health center treatment plans; others may not. For instance a consumer could decide that they want to try and find a job, receive counseling, or find an apartment (all areas where community mental health services traditionally can assist) and they may also decide that they want to spend more time outside of their apartment walking their dog, exercising, or spending time with friends (areas that can be worked on outside

of traditional assistance from a community mental health center). All of these goals can be identified by a consumer as elements that will help them in their recovery. Given that some of the goals consumers identify may fall within the domain of traditional mental health services, community mental health centers may want to consider implementing an EDSI within their agency. Consumers can take their self-directed recovery plan to their case-manager and engage in a shared-decision making process about the portions of their recovery plan that should be included in their official treatment plan.

### **Policy.**

Agencies such as CROs and community mental health centers are in place specifically to help individuals with psychiatric disabilities in their process of recovery within the community. In fact, these organizations have received federal mandates to do so (Department of Health and Human Services, 2003). The current study lends initial support to the contention that using an EDSI such as MY VOICE may lead to increases in consumer self-identified recovery. Mental health centers who wish to meet this mandate may be interested in implementing such a program.

In addition, mental health services are increasingly using electronic records, forms of communication, and treatment. Electronic decision support interventions have been found to be a cost effective means for engaging consumers in shared-decision making (Adams, 2006) and have consumer and governmental backing especially when they help facilitate shared-decision making or self-directed care (SAMHSA, 2004).

Community mental health centers are operating within a changing landscape regarding how mental health services are and will be delivered. The increasing use of electronic behavioral health interventions, a new diagnostic manual, a federal push to integrate of mental health care and physical health care within *mental health homes* (Scharf, Eberhart, Schmidt, Vaughan,

Dutta, Pincus, & Burnam, 2013), and the Obama administration's Affordable Care Act (Kocher, Emanuel & DeParle, 2010), will all dramatically alter the delivery structure of mental health services. Community mental health centers have an opportunity to participate in implementation and research of EDSI's which can better inform their current mental health practices and potentially help with integration efforts. For instance, the community mental health center which originally agreed to implement the MY VOICE program was not able to implement the MY VOICE program because they were overwhelmed by internal structural changes and challenges. There was a missed opportunity to pair data that is readily available at a community mental health center which is not readily available at a consumer run organization. Implementing EDSIs in a community mental health center may help centers utilize the consumer identified information within the EDSI to inform physical and mental health integration efforts meant to improve health outcomes.

### **Research.**

The results of this study have implications for research in several different domains. There are research implications for future investigations of the MY VOICE program, of EDSI's in general, and for SDC and SDM models.

### ***MY VOICE research.***

This pilot study provides initial evidence indicating that participation in the MY VOICE program may increase self-identified stage of recovery from mental illness. However, the exact mechanisms for this improvement in recovery are unknown. Future research is needed to determine whether or not the improvement in stage of recovery from those who participated in the MY VOICE intervention are captured by other mechanisms within the MY VOICE program, the peer support relationship, sense of community at the peer support center, or some

combination of these. These variables were not controlled for or analyzed in the present study. In addition, a qualitative study of those who participate in MY VOICE may provide clues about what participants find helpful in their recovery and about what variables to use as predictors during future controlled studies of the MY VOICE program. In addition, the present study was located at a peer support center thus limiting the generalizability of its findings. Future research into the MY VOICE program should investigate the efficacy of such a program when it is implemented within a community mental health center.

***Electronic decision support intervention research.***

The MY VOICE program is a consumer focused electronic decision support intervention. Consumer focused EDSI's are relatively new and are focused on helping consumers make decisions on their own, during, or prior to interactions with providers (Elwyn, Frosch, Volandes, Edwards & Montori, 2010). The Substance Abuse and Mental Health Services Administration (2010) has called for the development of additional decision aids and EDSIs. Research on EDSIs is in its infancy in the mental health arena, with only a few studies available. Thus far EDSI's have been used to help individuals with psychiatric disabilities decrease smoking (Brunette, et al., 2011), increase shared-decision making in treatment planning with case managers (Woltmann, et al., 2011), and to help consumers advocate for themselves with their medication prescriber (Deegan, 2007). The current study augments these studies by conducting a randomized trial to determine if an EDSI can help facilitate recovery, empowerment and self-determination. Future research of the MY VOICE program can continue to contribute the EDSI research literature. For instance a future MY VOICE research study could focus on determining if the long-term use of MY VOICE leads to long-term goal completion through stepwise completion of tasks. In addition, within the MY VOICE program consumers are given the

opportunity to make goals in eight different domains: Home/Daily Living, Assets/Finances/Insurance, Employment, Education, Supportive Relationship, Wellness/Health, Leisure/Recreation, and Spirituality/Culture. If it is found that an EDSI can help individuals reach goals in each of these domains it would broaden the newly developing EDSI research base into arenas it has not yet been tested.

### ***SDC and SDM Research***

The MY VOICE program was conceptualized as a potential precursor to a fully operational Self-Directed Care program in Kansas. This means that while the MY VOICE program does not include the budgeting portion of SDC it does explore the SDC concept of individualized/person-centered recovery planning. In particular, the recovery plan can contain goals that might not be included in a traditional treatment plan. The MY VOICE program was designed to potentially provide participants a resource which might help them stay organized in their attempts to achieve some of their recovery goals outside of the traditional case-management interaction. If they so choose, participants can also bring their recovery plan to their case-manager to advocate to obtain some of their goals through their regular treatment plan. This has the potential to expand the activities which participants view as possible and which can lead toward recovery. Future research on SDC could benefit from including MY VOICE or another EDSI as a component of the person centered planning program contained within SDC models and pair that with the budgeting allotments which can then fund the efforts and goals individuals set within the EDSI program.

One aspect of the shared-decision making that was not tested during the current study was the portion of the MY VOICE program which provides consumers with their own personal recovery plan and list of their personal strengths which can be used as a personal decision aid in

their advocacy with other treatment providers. For example, a participant could bring their personal recovery plan to their case-manager and compare it to their treatment plan. This may begin a dialogue about the consistencies and discrepancies between the two plans and lead to a shared-decision making process regarding the future course of treatment. There are many opportunities for shared decision making given the flexible format of the MY VOICE recovery plan which enables the consumer to share and discuss their plan with whomever they like. For instance, participants in the present study informally reported to peer support workers that they had shared their plans with case managers, spiritual advisors, health professionals, and family members, among others. Future qualitative research on the MY VOICE EDSI could augment the current SDM knowledge base by determining exactly who consumers decide to share their personal recovery plans with, if and how they use their personal recovery plan for advocacy and shared decisions, and what their experiences are when using their plans as a shared-decision making tool.

The MY VOICE program was also designed to explicitly include a focus on consumer strengths. Within the program strengths are identified and linked to both goals and tasks. Both SDC and SDM models could benefit from a future MY VOICE qualitative inquiry regarding how clients decide which strengths to identify and include in their recovery plans, what their experience is with identifying and linking strengths to their goals, and how they envision the strengths components of MY VOICE program influencing or not influencing their self-direction and shared decision making efforts.

### **Conclusions**

Individuals with psychiatric disabilities want to have more say in their care and treatment and are often participating in a mental health system that does not value their voice. The MY

VOICE strengths based and self-directed electronic decision support intervention is designed to help individuals with psychiatric disabilities increase their autonomy and voice in care. The statistically significant finding that those in the intervention group had higher scores on stage of recovery at Time 2 than those in the control group may mean that participation in the MY VOICE strengths-based and self-directed recovery EDSI may lead to changes in self-identified stage of recovery for participants. Replication of this research and continued investigations using rigorous protocols are needed. These findings are made with caution because of the study limitations and because the study was unable to detect what internal MY VOICE factors predicted the change in stage of recovery. However, this study lends some initial support for the contention that some, as of yet unidentified, element or elements of participation in the MY VOICE program may lead to positive changes in stage of recovery. Recovery is ultimately one of the goals that mental health systems are set up to achieve and what consumers both want and need.



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## Appendix A:

## Participant Characteristics Questionnaire

1. How old are you?\_\_\_\_\_
2. What is your gender? Male\_\_\_\_\_ Female\_\_\_\_\_
3. What is your primary mental health diagnosis (please check one)?
  - A. Schizophrenia B. Bipolar Disorder C. Major Depression D. Other\_\_\_\_\_
4. What is your race/ethnicity (please check one)?
  - A. American Indian or Alaska Native\_\_\_\_\_
  - B. Asian\_\_\_\_\_
  - C. Black or African American\_\_\_\_\_
  - D. Native Hawaiian or Other Pacific Islander\_\_\_\_\_
  - E. White\_\_\_\_\_
  - F. Hispanic or Latino\_\_\_\_\_
5. How long have you been attending SIDE?
  - \_\_\_\_\_ Less than 1 month,
  - \_\_\_\_\_ Between 1 month and 6 months
  - \_\_\_\_\_ Between 6 months and 1 year
  - \_\_\_\_\_ Between 1 year and 18 months
  - \_\_\_\_\_ Between 18 months and 2 years
  - \_\_\_\_\_ 2 years or more
6. How often do you attend SIDE?
  - \_\_\_\_\_ Daily \_\_\_\_\_ Every Other Day \_\_\_\_\_ Once or Twice a Week \_\_\_\_\_ Every Other Week
  - \_\_\_\_\_ Monthly \_\_\_\_\_ Less Than Once Per Month
7. What is the highest degree or level of school you have completed? If currently enrolled, mark the highest degree received.
  - \_\_\_\_\_ No schooling completed

- ☐ Nursery school to 8th grade
- ☐ 9th, 10<sup>th</sup>, or 11th grade. Or 12<sup>th</sup> grade but didn't graduate
- ☐ High school graduate - diploma or equivalent (for example: GED)
- ☐ Some college credit
- ☐ Associate degree
- ☐ Bachelor's degree
- ☐ Master's degree
- ☐ Doctorate degree

8. Are you currently employed?

- ☐ Disabled
- ☐ Unemployed
- ☐ Employed Part Time
- ☐ Employed Full Time.

9. What type of health insurance do you have?

- A. Private insurance   B. Medicaid/Medicare   C. Don't Have Insurance of Any Kind

10. Have you been psychiatrically hospitalized in the past year? Yes\_\_\_ No\_\_\_

11. How would you rate your ability to use computers?

- A. very poor, B. somewhat poor C. somewhat good, D. very good

12. How often do you use computers?

- A. Never B. Rarely C. Sometimes D. Often

13. Have you used the CommonGround© Decision Support Center? Yes\_\_\_ No\_\_\_

14. What types of services do you receive?

\_\_\_\_ Formal services (example: enrolled at a Community Mental Health Center and receive case-management, or therapy, or medication management).

Please list what services you receive:

---

\_\_\_\_ Only informal services (example: Talk to peers support workers, friends, family)

Please list what services you receive:

---

15. With 1 being very poor, 5 being average, and 10 being very good. How severe are the symptoms of your psychiatric disability right now? \_\_\_\_

Appendix B  
Empowerment Scale

**MAKING DECISIONS**

**Instructions:** Below are several statements relating to one's perspective on life and with having to make decisions. Please circle the number above the response that is closest to how you feel about the statement. Indicate how you feel now. First impressions are usually best. Do not spend a lot of time on any one question. Please be honest with yourself so that your answers reflect your true feelings.

PLEASE ANSWER ALL QUESTIONS  
BY CIRCLING THE NUMBER THAT BEST DESCRIBES HOW YOU FEEL.  
PLEASE CHECK ONLY ONE.

- 1. I can pretty much determine what will happen in my life.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

- 2. People have more power if they join together as a group.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

- 3. Getting angry about something never helps.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

- 4. I have a positive attitude toward myself.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

- 5. I am usually confident about the decisions I make.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**6. People have no right to get angry just because they don't like something.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**7. Most of the misfortunes in my life were due to bad luck.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**8. I see myself as a capable person.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**9. Making waves never gets you anywhere.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**10. People working together can have an effect on their community.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**11. I am often able to overcome barriers.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**12. I am generally optimistic about the future.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**13. When I make plans, I am almost certain to make them work.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**14. Usually I feel alone.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**15. Experts are in the best position to decide what people should do or learn.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**16. I am able to do things as well as most other people.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**17. I generally accomplish what I set out to do.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**18. People should try to live their lives the way they want to.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**19. I feel powerless most of the time.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree



**20. When I am unsure about something, I usually go along with the rest of the group.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**21. I feel I am a person of worth, at least on an equal basis with others.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**22. People have the right to make their own decisions, even if they are bad ones.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**23. I feel I have a number of good qualities.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**24. Very often a problem can be solved by taking action.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

**25. Working with others in my community can help to change things for the better.**

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

## Appendix C

**Self-Determination Scale**

## Instructions:

Please read the pairs of statements, one pair at a time, and think about which statement within the pair seems more true to you at this point in your life. Indicate the degree to which statement A feels true, relative to the degree that Statement B feels true, on the 5-point scale shown after each pair of statements. If statement A feels completely true and statement B feels completely untrue, the appropriate response would be 1. If the two statements are equally true, the appropriate response would be a 3. If only statement B feels true and so on.

1. A. I always feel like I choose the things I do.

B. I sometimes feel that it's not really me choosing the things I do.

**Only A feels true**    1       2       3       4       5       **Only B feels true**

2. A. My emotions sometimes seem alien to me.

B. My emotions always seem to belong to me.

**Only A feels true**    1       2       3       4       5       **Only B feels true**

3. A. I choose to do what I have to do.

B. I do what I have to, but I don't feel like it is really my choice.

**Only A feels true**    1       2       3       4       5       **Only B feels true**

4. A. I feel that I am rarely myself.

B. I feel like I am always completely myself.

**Only A feels true**    1       2       3       4       5       **Only B feels true**

5. A. I do what I do because it interests me.

B. I do what I do because I have to.

**Only A feels true**    1       2       3       4       5       **Only B feels true**

6. A. When I accomplish something, I often feel it wasn't really me who did it.

B. When I accomplish something, I always feel it's me who did it.

**Only A feels true**    1       2       3       4       5       **Only B feels true**

7. A. I am free to do whatever I decide to do.

B. What I do is often not what I'd choose to do.

**Only A feels true**    1       2       3       4       5       **Only B feels true**

8. A. My body sometimes feels like a stranger to me.

B. My body always feels like me.

**Only A feels true**    1       2       3       4       5       **Only B feels true**

9. A. I feel pretty free to do whatever I choose to.

B. I often do things that I don't choose to do.

**Only A feels true**    1       2       3       4       5       **Only B feels true**

10. A. Sometimes I look into the mirror and see a stranger.

B. When I look into the mirror I see myself.

**Only A feels true**    1       2       3       4       5       **Only B feels true**

## Appendix D

## Self-Identified Stage of Recovery Scale (SIS-R)

Code.....

Andresen, R, Caputi, P & Oades, L (2010). Do clinical outcome measures assess consumer-defined recovery? *Psychiatry Research*, 177, 309-317. For enquiries about the SISR, please contact Retta Andresen at: [retta@uow.edu.au](mailto:retta@uow.edu.au).

## PART A

People who are told they have a serious illness can feel differently about life with the illness at different times. Below are five statements describing how people may feel at times when living with a mental illness.

Please read all five statements (A-E) before answering the question that follows.

A) "I don't think people can recover from mental illness. I feel that my life is out of my control, and there is nothing I can do to help myself."

B) "I have just recently realised that people can recover from serious mental illness. I am just starting to think it may be possible for me to help myself."

C) "I am starting to learn how I can overcome the illness. I've decided I'm going to start getting on with my life."

D) "I can manage the illness reasonably well now. I am doing OK, and feel fairly positive about the future."

E) "I feel I am in control of my health and my life now. I am doing very well and the future looks bright."

Of the five statements above, which one would you say most closely describes how you have been feeling over the past month about life with the illness? Tick the box next to that statement.

Appendix E  
The MY VOICE Pilot Study  
Informed consent form

## INTRODUCTION

The School of Social Welfare at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with this unit, the services it may provide to you, or the University of Kansas.

## PURPOSE OF THE STUDY

The purpose of this study is to learn whether the MY VOICE program is useful for individuals with psychiatric disabilities in planning their own recovery. It is hoped that the insights gained from this study will help researchers, administrators and providers of mental health services improve the quality of the MY VOICE program.

## PROCEDURES

You are participating in a study which will assign you to either use the MY VOICE program immediately or use the MY VOICE program after waiting two months. You are agreeing to use the software program to assess your personal strengths, develop recovery goals, and pair your strengths to your goals and develop initial tasks toward completion of your recovery goals.

Prior to using the MY VOICE program you will be interviewed by a researcher from KU (Trevor J. Manthey) who will ask you to fill out some forms called a pretest. At this time you will be given a \$20 dollar gift card for participating. After a two month period of time you will be asked to have another interview with the same KU researcher who will have you fill out the same forms you filled out during the first interview. During the two month time period you will have either been using the MY VOICE program, or you will have been assigned to the group who was not using the program. At the time of the second interview you will receive a second \$20 dollar gift card for participating. After the second interview both groups of individuals will use the MY VOICE program for an additional two months. This means that if you haven't use the MY VOICE program prior to this you will begin using the program and if you were already using the MY VOICE program you will continue to do so. At the conclusion of this final two month period you will be interviewed for a final time by the same KU researcher who will have you fill out the forms you filled out during the first to interviews a final time. At this time you will also receive a final gift card for \$20 dollars. It is anticipated that the interview with the KU researcher would take between 30 minutes to an hour.

The researcher from KU will use the information you provide within the MY VOICE program and on the forms you fill out during the interviews to evaluate the effectiveness of the MY VOICE program.

Findings from this study will be reported to University of Kansas School of Social Welfare, and may be reported to other professional audiences.

## RISKS

There are few significant risks associated with participation in this study. Information provided in MY VOICE program and the interviews will be confidential. All information will be analyzed in aggregate and your individual level data will be de-identified. The KU research has been trained in research ethics.

## BENEFITS

While there may be no direct benefits for participating, it is anticipated the researcher may publish the findings from this study and it may help improve services that are developed based off of this information. For instance, future iterations of the MY VOICE program may be developed based on the information that is gathered during this study.

## PAYMENT TO PARTICIPANTS

There are three \$20 gift cards being provided at three separate points during this research project. During the pretest interview, the first follow-up interview, and the final follow up interview. Investigators may ask for your social security number in order to comply with federal and state tax and accounting regulations.

## PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any publication or presentation with the information collected about you or with the research findings from this study. Instead, the researcher(s) will use a study number or a pseudonym rather than your name. Your identifiable information will not be shared unless required by law or you give written permission.

## REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from your community mental health agency. However, if you refuse to sign, you cannot participate in this study.

## CANCELLING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose information collected about you, in writing, at any time, by sending your written request to: Trevor J. Manthey, 1545 Lilac Lane, School of Social Welfare, University of Kansas, Lawrence, KS 66044. If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the

research team may use and disclose information that was gathered before they received your cancellation, as described above.

## QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to Trevor J. Manthey; his contact information is listed at the end of this consent form.

## PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call 785-864-8946 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email [mdenning@ku.edu](mailto:mdenning@ku.edu).

I agree to take part in this study as a research participant. By my signature I affirm that I have received a copy of this Consent and Authorization form.

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Type/Print Participant's Name

---

Date

---

Participant's Signature

## **Researcher Contact Information:**

Trevor Manthey, MSW  
KU School of Social Welfare.  
1545 Lilac Lane  
Lawrence, KS 66044  
208-818-8718  
[trevormanthey@gmail.com](mailto:trevormanthey@gmail.com)